A Silent Cry: Paediatric Palliative Care in Ireland

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Candidate Thesis Declaration

I declare that this thesis, which I submit to RCSI for examination in consideration of the award of a higher degree MSc in Healthcare Ethics and Law is my own personal effort. Where any of the content presented is the result of input or data from a related collaborative research programme this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge does not breach copyright law, and has not been taken from other sources except where such work has been cited and acknowledged within the text.

Signed _____________________

Student Number 14125803

Date 22nd of July 2016.
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<tbody>
<tr>
<td>ATD</td>
<td>Advanced Treatment Discussion</td>
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<td>ACT</td>
<td>Association for Children with Life Threatening or Terminal Conditions</td>
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<td>CDC</td>
<td>Centres for Disease Control and Prevention</td>
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<td>CON</td>
<td>Childrens’ Outreach Nurse</td>
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<td>CBPPC</td>
<td>Community Based Paediatric Palliative Care</td>
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<tr>
<td>DoHC</td>
<td>Department of Health and Children</td>
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<tr>
<td>DNR</td>
<td>Do-not-resuscitate</td>
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<td>EoL</td>
<td>End of Life</td>
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<td>EAPC</td>
<td>European Association of Palliative Care</td>
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<td>EEA</td>
<td>European Economic Area</td>
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<td>EU</td>
<td>European Union</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>HSE</td>
<td>Health Service Executive</td>
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<td>ICU</td>
<td>Intensive Care Unit</td>
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<tr>
<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
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<td>IAPC</td>
<td>Irish Association of Palliative Care</td>
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<td>IHF</td>
<td>Irish Hospice Foundation</td>
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<td>IMC</td>
<td>Irish Medical Council</td>
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<tr>
<td>LFA</td>
<td>Lethal Foetal Abnormalities</td>
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<td>LLC</td>
<td>Life Limiting Condition</td>
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<td>LM</td>
<td>Lethal Malformation</td>
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<td>LST</td>
<td>Life-Sustaining Treatments</td>
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<td>MDT</td>
<td>Multidisciplinary Team</td>
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<td>Acronym</td>
<td>Description</td>
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<tr>
<td>NDC</td>
<td>National Development Committee for Children's Palliative Care</td>
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<td>PHCT</td>
<td>Primary Healthcare Team</td>
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<td>PHN</td>
<td>Public Health Nurse</td>
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<td>POONS</td>
<td>Paediatric Oncology Outreach Nurse Specialist</td>
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<td>PPC</td>
<td>Paediatric Palliative Care</td>
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<td>QoL</td>
<td>Quality of life</td>
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<td>TAS</td>
<td>Treatment Abroad Scheme</td>
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<td>ToP</td>
<td>Termination of Pregnancy</td>
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<td>UK</td>
<td>United Kingdom</td>
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<td>UN</td>
<td>United Nations</td>
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<td>UNHRC</td>
<td>United Nations Human Rights Committee</td>
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<td>USA</td>
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Abstract

Paediatric Palliative Care, being an evolving speciality with the unique challenges of children living longer because of advancing technology, has met with some difficult hurdles. With a variety of conditions, which are unique to paediatrics, this has led to many ethical and legal dilemmas.

Health policy and easy access to information regarding treatment options, has led to a more autonomous patient and family. The need for a Paediatric Palliative Care service has resulted.

Paediatric Palliative Care, whilst still in its infancy, has met with many challenges, but the overarching benefits for the child and family has helped to secure its place as a medical speciality.

The evolution of the service in Ireland is explored, along with the barriers faced and the plans for the future. In 2001 the Department of Health and Children, after assessing the palliative care services nationwide, realised that children with palliative care needs were unique to adults. Out of this the ‘Palliative Care Needs Assessment for Children’ document was published in 2005. Many challenges ensued, but with determination and compassion, Ireland has made steady progress in getting an effective equitable service off the ground. Progress to date and the plans for the future will be identified.

The legal and ethical aspects when caring for a child with palliative care needs and their family are highly complex. These complexities, in conjunction with the dilemmas facing the healthcare teams providing paediatric palliative care are investigated.
I would like to thank my supervisor, Dr. Joan Cunningham, for her patience, encouragement and expertise. I wish to express gratitude to Prof. David Smith, who always delivered a thought provoking and highly stimulating class, and to the many fantastic lecturers, all with a wealth of knowledge.

I would also like to express my absolute appreciation for my children, Cillian, Aoibhe and Aisling and to Darren, my best friend, for their belief and patience. A special thanks to both sets of grandparents without whose help and support, I would still be writing.
Introduction

‘We will do all we can not only to help you die peacefully, but also to live until you die’

Cicely Saunders

Children should not die. It goes against nature. In an ideal world we would have no need for children’s palliative care, unfortunately, this isn’t so. Twenty first century medicine, with its advancing pharmacological and technical developments, has led to more neonates and children surviving against the odds and living with life limiting conditions. It is the silent cry of these little children that we must open our ears to.

The Committee on Bioethics and Committee on Hospital Care (2000) states

‘Palliative care seeks to enhance quality of life in the face of an untimely terminal condition. Palliative care treatments focus on the relief of symptoms (e.g. pain, dyspnoea) and conditions (e.g. loneliness) that cause distress and detract from the child’s enjoyment of life.’

Palliative care is not only for ‘End of Life’ care. It is very important that we focus on that statement. It is a common belief, not only amongst lay people, but also within the healthcare profession that palliative care means ‘giving up’, that ‘there is no more we can do’, and that ‘the child is dying’. However, palliative care is a philosophy of care. It is about offering comfort, support and dignity to those who are most vulnerable. It is about enhancing the child’s quality of life, enabling them to live to their full potential and reach their goals, even though those goals may change throughout the course of their illness. The most vulnerable people in our society are quite often children.

The World Health Organisation in 1998(a), defines Palliative Care as

‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early
identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’.

The Association for Children with Life Threatening or Terminal Conditions and their families (ACT)/ Together for Short Lives which is the gold standard for Paediatric Palliative Care (PPC), have given a comprehensive definition which will be explored in depth in chapter one.

Palliative care is also about the families of these children. It recognises the child within the family unit. It seeks to bring solace to these grief stricken families by supporting them to enable their child to leave their mark on the world and live their lives to the end. Palliative care should not be feared, it should be embraced. It should be utilised in conjunction with treatments aimed at curing or controlling the child’s illness.

‘... no clear distinction is made between curative attempts to improve the patient’s quality of life and extend its duration, and purely “palliative” measures; both approaches coexist and one prevails over the other depending on the stage of the disease and the situation.’ (Benini et al. 2008)

What do these definitions of palliative care mean for children and their families living with life-limiting conditions in Ireland? What services are available and who has access to them? The ACT definition is considered the gold standard of care for children with palliative care needs. The definition of paediatric palliative care will be investigated in the first chapter of this dissertation. Each section of the definition will be examined and how we as healthcare professionals can serve to implement this will be explored.

In the second chapter the evolution of paediatric palliative care in Ireland will be outlined. Ireland has made great strides in advancing an effective, equitable palliative care service for children with life-limiting conditions. The reports and policies specifically within the Irish context are shown and their implementation explained. The complementary relationship between the voluntary agencies and statutory bodies with an interest in the development of the service are outlined.
Paediatric palliative care faces many challenges. Palliative care carries a stigma. It continues to be associated with end-of-life care. Parents do not wish to acknowledge that their precious child needs this service and often a referral serves as a reminder to the healthcare team that cure is not always possible. An integrated approach to the child’s care encompassing many team members is the best standard for care but may lead to difficulties for the child and family to navigate within the system. Ineffective communication skills can bring about further barriers for an effective service. These barriers are considered throughout chapter three and an account of the recommendations to help to overcome them is outlined.

The benefits of paediatric palliative care for the child, family and health service are boundless. Chapter four gives a detailed account of these benefits with a particular focus on the benefit of an early referral to the overall quality of life for the child and family. An early referral allows for a trusting relationship to be formed between the team and the child and family. This allows for open honest communication and facilitates the development of a child specific plan, incorporating choices for end-of-life care. The advantages of a multidisciplinary team approach are detailed. The cost effectiveness of the service is identified both in the hospital and in the community setting.

Chapter five considers the legislation concerning the rights of the child and how best to protect their interests. Considering the benefits which a palliative care referral can offer, it can be argued that a child has the right to access this service. In certain circumstances it will be questioned as to which available treatment options are in the best interest of the child. This dilemma is explored, along with that of withdrawing or withholding of care in the legal setting. The competency of a child is examined in relation to giving consent to treatments and research. Also the controversial legislation regarding abortion in Ireland is laid out.

The ethics of palliative care is very important. It guides healthcare professionals in times of difficult decision making. Chapter six gives an in depth account of the ethical issues in paediatric palliative care. These issues
are examined under the four principles; respect for autonomy, beneficence, maleficence and justice. Each principle shares an equal proportion of importance at different stages in the child’s illness and in guiding certain decisions.

A case study is presented to illustrate some of the legal and ethical dilemmas that may occur in the course of providing medical care to a child with a life limiting illness. Re Charlotte Wyatt is the case outlined in chapter seven.

Finally, some recommendations are made to ensure that paediatric palliative care continues to grow and extend to all of our nations children who require and deserve a gold standard service.
Chapter 1: The definition of Paediatric Palliative Care

Definition
There are many different but similar definitions of Paediatric Palliative Care (PPC) available in the literature. The Association for Children with Life Threatening or Terminal Conditions and Their Families (ACT)/ Together for Short Lives definition, which is the United Kingdom’s, pioneer organisation leading PPC worldwide, and is probably the gold standard for those working in this specialised area.

Palliative care for children and young people with life-limiting conditions

“...is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement”

(ACT/Royal College of Paediatrics and Child Health Child Health, 2003)

In this chapter, the author will examine each part of this definition and evaluate it. Each sentence has a very clear meaning for the children and families who require palliative care. It also serves to guide us, as healthcare professionals on the goals and standards of care which we must strive to achieve for each and every one of these children. It informs us about using an integrated approach, family centeredness, caring for the child as a whole person, and care from the time of diagnosis along their entire journey, through to death and bereavement. To facilitate the level of support required by these children with complex care needs a holistic and integrated Multidisciplinary Team (MDT) approach is vital, and will be explored further within this dissertation.

...‘active and total approach to care...’

What does this mean? Caring for a child with a life limiting condition requires multiple interventions and a healthcare professional with a highly tuned skill set. Active care implies that palliative care is running alongside treatment aimed at curing disease or prolonging the child’s life. The ‘total approach to care’ involves the whole child as a person, physically, psychosocially, culturally including their beliefs and values and most importantly includes
their whole family. It advocates that we promote palliative care as an integrated approach to the child and family’s healing. It guides us in developing a parallel plan, for the child’s care, from the time of diagnosis through to end of life care and into bereavement. The goals of treatment may change for both the healthcare professional and the child and family along the way, and we must adapt to those changing needs. Friebert and Williams (2015) stated that, ‘Paediatric palliative/hospice care is provided along with concurrent disease-modifying therapy when disease-modifying therapy is appropriate or as the main focus of care when disease-modifying therapies are no longer effective, and comfort is of utmost importance.’

‘... embracing physical, emotional, social and spiritual elements.’ This is a very important statement. It describes the attributes that make up a person. It guides us, as healthcare professionals to treat the entire person and not just the visible symptoms. ‘The term “palliative” is derived from the Latin word pallium meaning a cloak. Palliative care aims to cloak the patient’s symptoms and provide comfort even when treatments aimed at cure are no longer possible’ (Muckaden et al., 2011) Each child requiring palliative care is unique. Even children with the same condition may have very different needs. Their needs are influenced by their age, cognition and level of support they have in their lives. It is also influenced greatly by past experiences and the people they encounter along their journey. As healthcare professionals it is very important that we view each child as an individual and do not compare cases. Nicholl and Tracey (2015) addressed this when they said, ‘The requirement is that care is tailored to each child’s developmental stage, including language and cognition as well as physical development.’

‘... enhancement of quality of life for the child...’ How does one define quality of life? It is a very subjective term. Quality of life has a different meaning for different people. It varies greatly for children and families depending on the stage of their illness, their beliefs, culture and many more individual variables. The World Health Organisation (WHO) (1995), cited by O’Quinn and Giambra (pp.1405, 2014), defines quality of life as ‘an individual’s perception of their position in life, in the context of the culture and value
systems in which they live and in relation to their goals, expectations, standards and concerns’. Health related quality of life is slightly different and has more consequence for healthcare professionals. According to the Centres for Disease Control and Prevention (CDC) (2016), ‘Health Related Quality Of Life is a broad multidimensional concept that usually includes self-reported measures of physical and mental health’. Quality of life must be respected in light of values and the particular circumstances of each individual child and family. ‘This perspective supports efforts to help patients and their families find meaning in their living or dying and realise goals that facilitate the experience of meaning.’ (Rushton 2005)

... ‘support for the family.’ When caring for children in any context, but perhaps even more so when caring for a child who is life limited, the family require very special attention. Zimmermann et.al, (2016) describe this when they say, ‘When facing the death of a child, parents experience an unimaginably painful life event and severe crisis that affects the whole family for life.’ Each member of the palliative care team, play an important role in helping families through their journey of diagnosis, illness, end of life care and into bereavement. The duration of the journey varies greatly from child to child. The role we, as healthcare professionals play can have a lasting impact on how the family deal with bereavement and live the rest of their lives. ‘The needs of families must be attended to both during the illness and after the child’s death to improve their ability to survive the ordeal intact.’ Committee on Bioethics and Committee on Hospital Care, (2000)

‘... management of distressing symptoms...’ This is one part of the definition that resonates strongly with us all when we think of palliative care. It may be more difficult, for healthcare professionals to address in PPC however. When caring for children with life limiting conditions, there are a vast number of different illnesses and symptoms to be managed and the complexity of this is exacerbated by the diversity in age range and cognitive ability, from neonate to adolescent. Adult palliative care has its foundations set in oncology care where the course of the disease and associated symptoms are generally predictable, whereas children, who are life limited do not survive into adulthood and quite often present with rare conditions. ‘... paediatric services
look after children with a diverse range of life-limiting conditions, most commonly genetic/congenital diseases (41%) and neuromuscular conditions (39%).’ (Spathis et al. 2012) Neonates, babies and children with neurological impairments are mainly non-verbal. This poses a specific communication hurdle for the healthcare professional when trying to alleviate distressing symptoms. This can cause a lot of anxiety for parents and takes time for the healthcare professional to build a relationship with the child and family to enable them to best assess and treat these symptoms. Zimmermann et al. (2016) described this by saying, ‘Parents of children with neurological impairments face many challenges. Symptom management can be a source of distress for parents as the children are mostly non-verbal and the potential for suffering is high due to a variety of impairments.’

‘...provision of respite...’ According to the Committee on Bioethics and Committee on Hospital care (2000) respite care is, ‘the provision of care to an ill child (in his or her usual state of health) by qualified caregivers other than family members, allows the family time to rest and renew, whether for hours or days, on a schedule, or intermittently as needed.’ Caring for a chronically ill child is stressful and very demanding. It has a major impact on parents and siblings. Families in these situations are at risk from burnout. Spathis et al. (2012) concurred with this by saying ‘Families carry a particularly heavy burden, as long-term primary care givers. Related psychosocial morbidity, such as depression, divorce and unemployment, is prevalent.’ Respite in the home, hospice, or ‘home from home’ is hugely important for children with PPC needs. It allows families time to regain their energy, making coping with the situation a little more feasible.

‘...care through death and bereavement.’ The loss of a child is the most profound loss anyone will ever face. It goes against nature. Children and parents need competent, professional support at this difficult time. Rushton (2005) confirmed this by saying, ‘Being with a terminally ill child and his or her family requires the ability to be attuned to the needs of everyone involved, to the atmosphere surrounding care, and to the context of the situation.’ The death of a child is highly emotive for all involved. Families require compassionate support at this stage of the journey. When supported,
families feel safe and reassured. ‘Authentic presence involves the capacity to
stay with the child and family until the end of the journey, experiencing
whatever feelings are expressed, from loss to love, awkwardness to anger.’
(Rushton 2005) We, as healthcare professionals, have only one chance to
get care right for each family along their journey with their child, with a life
limiting condition. Our interaction with them may have a huge impact on their
living afterwards, and bereavement care plays an important role here.
‘Promoting the best possible outcomes after such a devastating experience
has implications for the whole family, the healthcare system and society.’
(Zimmermann et.al, 2016)

**Life Limiting/Life Threatening Conditions**

‘Palliative care was associated, initially, with oncology services, but has
gradually evolved to encompass all life-limiting conditions.’ (Department of
Health and Children (DoHC), 2009) This leads on to the discussion as to
what the difference is, if any, between life-limiting conditions and life-
threatening conditions. Do both categories warrant palliative care? Are both
categories being offered palliative care?

The Together for Short Lives definition (2003) explains Life-limiting /life-
shortening conditions as those ‘for which there is no reasonable hope of cure
and from which children or young people will die. Some of these conditions
cause progressive deterioration rendering the child increasingly dependent
on parents and carers’, and life-threatening conditions as those ‘for which
curative treatment may be feasible but can fail, such as cancer. Children in
long-term remission or following successful curative treatment are not
included’. However, due to the ambiguity of different classifications of life
limiting or life threatening conditions and the benefits to be gained by such a
referral, it can be argued that all children with any such diagnosis would in
fact benefit from a referral. ‘...in children’s palliative care, the disease
trajectory differs, the child’s diagnosis, symptoms and presentation impact on
their service requirements from the point of diagnosis (or suspicion that
something is wrong) to end of life and the identification of the need for palliative care may be problematic.’ (Nicholl and Tracey, 2015) The ACT categories for life limiting/life threatening conditions are available in Appendix 3.

**Integrated Care**

These definitions are important as it guides healthcare professionals in recognising the children who require a referral to the PPC team even though they may be also availing of active treatment. This is called ‘parallel planning’ or an ‘integrated approach’. Rushton (2005) explained an integrated approach as ‘Its goal is to enable the patient and the patient’s family to adjust to the changes in health in their own unique way’. This helps to prevent families from experiencing a sudden shift in treatment from curative to palliative. When this happens families often feel as though they are being abandoned by their healthcare team or that their child is no longer receiving the best possible care. Again Rushton (2005) describes integrated care eloquently when she says ‘it insists that a meaningful, interactive relationship among patient, family, and healthcare professionals provides the foundation for advocacy and treatment.’

**Multidisciplinary Team Approach**

The definition of PPC highlights several important points. It stresses the importance of a multidisciplinary team approach in best caring for a child with an incurable illness. For the purpose of this dissertation MDT is a team of health and social care professionals working together to provide holistic care. The MDT in Paediatric Palliative Care may include, foetal medicine consultants, obstetricians, neonatologists, general paediatricians, paediatric consultant with a special interest in palliative care, neonatal nurses, nurses, Childrens’ Outreach Nurse (CON), allied health professionals, bereavement care specialists, bereavement care staff including chaplains, medical social workers as well as the General Practitioner (GP), adult palliative homecare teams, and Public Health Nurse (PHN). Crozier & Hancock (2012) state that ‘...communication between providers is important to give families a
consistent message, and palliative care teams often assist in facilitating this communication'. All staff play a central role in supporting and giving information to parents who receive bad news and it is essential that a ‘key worker’ from within the MDT is identified to the family. In Ireland the role of the CON has been recognised as that of key worker which was identified as a need by the families in 'A Palliative Care needs Assessment for Children' (Chapter 39, 2005)

As Mellor et al., (2011) stated ‘The underlying philosophy of palliative care overlaps in many ways with the approach taken by all professionals working in paediatrics.’ PPC is a philosophy of care which should be embraced by all healthcare professionals caring for a child with a life limiting condition. It can be provided in the hospital, hospice or home. Children and families who receive a life limiting diagnosis can have greatly different experiences. The children can have many different symptoms. They, together with their families, require a myriad of interventions throughout the course of the illness. Collaboration and communication is essential in providing a quality service to these vulnerable children. Rushton (2005), highlighted this by saying, ‘Healthcare professionals must value the unique contributions of an array of practitioners and healers and involve them in the healing process.’ In the Irish context, an integrated approach has been advocated for in Palliative Care for Children with Life-Limiting Conditions in Ireland- A National Policy (2009)

‘The integration and co-ordination of services is a vital prerequisite to providing an effective and efficient seamless palliative care service for children with life limiting conditions and their families. Providing continuity of care through the integration of neonatal, acute paediatric through to primary care, secondary and tertiary hospitals, voluntary services and respite centres requires knowledge of the healthcare system.’(DoHC 2009)

Whilst palliative care does not cure a condition or disease it may offer healing to the child and family. As the child and family negate their way through their journey from diagnosis to the realisation that cure is not possible, healthcare professionals providing palliative care will support them to achieve a quality of life and hopefully, a quality of death. It offers families
choices and allows them to follow the treatment path which best suits their values as a family. Due to medical advances there are more aggressive treatment options available and the child’s life may become dependent on technological equipment. Palliative care is not about forcing families into the healthcare professionals’ way of thinking but facilitating the family to reach a decision in which mutual goals may be achieved and respected. ‘Providing a safe environment for patients and families to explore their own sense of meaning or understanding of the situation can have lasting benefits’ (Michelson and Steinhorn 2007)

**Differences between Adult and Paediatric Palliative Care**

There are similarities in the principles of adult palliative care and PPC. In Ireland the speciality of PPC is still developing, therefore adult services are being utilised to provide a service to children requiring palliative care. However, there are major differences between the two services, ‘In adults, the patient’s illness trajectory and pathway is often clearly defined whereas children’s palliative care presents the challenge of providing active treatment, (as many infants, children and young people have diseases for which the outcome is uncertain where cure remains a distinct possibility) while simultaneously providing palliative care.’ (Nicholl and Tracey, 2015) When caring for children, their families are a central component. ‘In the field of paediatrics especially, person-centeredness must be extended to family-centeredness, with the child and family as the unit of care.’ (Zimmermann et.al, 2016) As the course of the illness may be prolonged and unpredictable, the healthcare team must be adaptable to the changing and developing needs of the child and family. Spathis et.al, (2012) described this when they said, ‘Children, unlike adults, tend to continue to develop physically and cognitively throughout their illness, and families expect flexible, responsive support at the location of the child, whether at home, school or hospital.’ This is a very important factor in PPC.
Conclusion

Overall, the ACT/Together for Short Lives definition of PPC is very comprehensive. It encompasses all aspects of the child and family, from their values and beliefs to their symptoms and their individual level of support required. It advocates the use of an integrated approach of both curative and palliative care and strongly promotes the importance of a multidisciplinary team approach. The World Health Organisation (1998a) compounded this definition by stating ‘Palliative Care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.’ It also states that ‘Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources...’ Ireland’s PPC service is active in embracing an integrated care pathway supported by the MDT, and focuses on the individual needs of each child and their family unit; this will be explored further in the subsequent chapters.
Chapter 2: The Evolution of Paediatric Palliative Care in Ireland

Historically in Ireland

This anonymous 16th century writing summarises the philosophy of palliative care eloquently,

‘To cure, occasionally; to relieve, often; to comfort, always!’

Children’s palliative care is a relatively new phenomenon. It has developed unfortunately in response to a need. Neonates and children that would previously have died are surviving in an era of medical technological advancement. In Ireland there is currently no national database accurately collecting all data on children living and dying with a life-limiting condition. ‘Utilising recent UK data has resulted in a significant upward revision of the estimated prevalence of children in Ireland with a life-limiting condition. It is estimated that the current number stands at 3,840 children. (The National Development Committee for Children’s Palliative Care (NDC) 2016) ‘We estimate that more than 40,000 children (0-19 years) in England in 2009/2010 were living with a Life Limiting Condition (LLC).’(Fraser et al, 2012)

In 1995 Ireland was the second European country to recognise palliative care as a medical speciality. The Irish Association of Palliative Care (IAPC) was established in the early 1990’s, with its role to promote the development of palliative care services in Ireland. These developments were all based in the adult arena, with children who had palliative care needs being cared for by the adult teams.

In 2001, the Department of Health and Children published a ‘Report of the National Advisory Committee on Palliative Care.’ It made two key recommendations in relation to paediatric palliative care;

- The medical and nursing care of children in hospitals should be the responsibility of paediatric-trained medical and nursing staff.
- There should be close co-operation and liaison between paediatric and specialist palliative care services in each health board area.
As a result of this report a working group were tasked with assessing the need for developing a specialist palliative care service for children. Out of this the ‘Palliative Care Needs Assessment for Children’ document was published in 2005.

**A Collaborative approach**

The development of children’s palliative care in Ireland is underpinned by a collaborative approach between statutory agencies and voluntary organisations. In 2005, the Irish Hospice Foundation in association with the Department of Health and Children published ‘A Palliative Care needs Assessment for Children’. A key finding of this nationwide study was that most families voiced a preference for their child to be cared for at home in the family unit and if possible, to die at home surrounded by loved ones. This report highlighted a need for coordinated care for children and families. Parents also stressed the need for a key worker. The family’s need for suitable respite and home care services were also emphasised.

**National Policy**

Moving forward from this, ‘Palliative Care for Children with Life-Limiting Conditions in Ireland - A National Policy (2009) was published by the Department of Health and Children. The development of services for children with a life-limiting condition and their families was made feasible through the vision and framework of this policy. This document is divided into three sections. The first section looks at palliative care for children with Life-Limiting Conditions. It examines national and international developments in this relatively new healthcare speciality. The second section gives an account of services provided for children at the time. The third section has given rise to the development of palliative care services for children in Ireland thus far.

As recommended by this policy a National Development Committee for Children’s Palliative Care (NDC) was established in 2010, whose achievements are discussed below. Both statutory and voluntary
organisations with involvement in caring for children with Life-Limiting Conditions are represented on this committee. The committee reports to the HSE at National Director Level.

**Achievements of National Development Committee for Children's Palliative Care (NDC)**

In 2011 Ireland’s first Paediatric Consultant with a Special Interest in Palliative Care was appointed in Our Lady’s Hospital for Sick Children in Crumlin. This consultant has a nationwide remit to consult with any team providing palliative care to a child. Eight Children’s Outreach Nurses for children with Life-Limiting Conditions were appointed and based in acute hospital paediatric units across the country. A further two posts have been approved in 2016. A national Clinical Governance and Development Network to oversee the development of referral guidelines, care pathways and protocols have been established. Education and training programmes for healthcare professionals providing care to children with a LLC and their families have been developed and rolled out nationally. These programmes are in alignment with the national Palliative Care Competence Framework which was published by the HSE in 2014. It states that,

‘Applying the core and specific competences in practice, will help all health care staff (based in a hospital, hospice, GP practice, primary care centre or a community based setting) working with social care partners, to recognise their role in palliative care and to develop their own quality improvements’. (HSE, 2014)

**Other Developments**

Other developments arising from the policy include the Completion of a nationwide needs assessment of respite for children with life-limiting conditions requiring palliative care, this led to the publication of ‘Respite Services for Children with Life-limiting Conditions and their Families in Ireland- A National Needs Assessment (2013)’, an external evaluation of the
children’s palliative care programme, the results of this evaluation will be available in late 2016, development of an all-Ireland integrated children’s palliative care website, support and development of research in children’s palliative care, and the development of an Education and Governance Framework to guide and support the work of the Children’s Outreach Nurses.

**Prevalence of Life Limiting Conditions in Ireland and the UK**

‘In the UK, demand for paediatric palliative care services has quadrupled in the past 15 years, and approximately 23,500 children are likely to require access to palliative-hospice care services annually, according to the UK Department of Health Statistics.’ (Gethins, 2012) These figures are comparable to Ireland and as stated, have been utilised in the approximation of figures in Ireland in the absence of accurate data currently being recorded. The NDC (2016) also states that ‘Approximately 350 children die in Ireland each year due to a life-limiting condition. 40% of children who die in Ireland die within the first week of life.’ These figures have had, and continue to have a major impact on the development of children’s palliative care services.

**Development of Neonatal Palliative Care Services**

As a result of the overwhelming neonatal fatalities, national standards for bereavement care following pregnancy loss and perinatal death have been developed by the HSE. These standards will be the cornerstone for the development of an essential palliative care approach for women, babies and their families experiencing loss in Ireland’s maternity services.
Resources

Ireland has, and continues to experience challenges in relation to the
development of a children’s palliative care service that is well resourced and
equitable. The challenges Ireland faces are experienced globally. The
numbers of children requiring palliative care are relatively small and it is
therefore difficult to prove the cost effectiveness of such a service. Palliative
care requires time for relationship building, and time equates to cost.
‘Presence is not traditionally factored into time and cost analyses of nursing
services because it is not easily quantifiable.’ (Rushton 2005) The cost
effectiveness of children’s palliative care will be examined extensively in a
subsequent chapter.

Geographical Location

Access to services may prove difficult for families living in rural Ireland.
Children may not be well enough to travel to a centre for care, or it may be
difficult for the family for varying other reasons such as, cost of travel, work,
and effect on siblings. The Children’s Outreach Nurse service and homecare
teams have helped to ease this, but for families who are living in a remote
geographical location, this still can limit their child’s care. Currently there are
eight CONs, each of whom has remit over a large geographical area, this
impacts on the equity of the service being delivered to the children who live
far from regional and tertiary referral units. Isolated locations also have an
effect on sourcing competent, trained healthcare professionals to provide
care for the child in their own home. Caring for a child with a life-limiting
condition requires personnel with a very specific skill set and experience.
Children’s palliative care embraces the whole family. All family members will
be affected by the child’s diagnosis, such as grandparents, but none more so
than the parents and siblings as they anticipate the journey and
bereavement. ‘The aim of palliative care is to enhance quality of life and,
wherever possible to positively influence the course of illness. Palliative care
also extends support to families to help them cope with their family member’s
illness and their own experience of grief and loss’. (HSE 2014)
Medical Speciality and Children’s Hospice

Dame Cicely Saunders founded the palliative care movement in the UK. She established the first hospice dedicated to research, teaching and expert pain and symptom control, combined with compassionate care, St. Christophers, in 1967. She is universally recognised as the founder of the modern hospice movement and received many honours and awards for her work. In 1987, her work contributed also to the decision by The Royal College of Physicians to recognise Palliative Care as a new medical specialty. In Ireland palliative care was recognised as a specialty in 1995. Paediatric palliative care is much more recent, with Ireland’s first, and only, Paediatric Consultant with a Special Interest in Palliative Care being appointed in 2011.

Helen House was the world’s first children’s hospice, opening in November 1982, in the UK. Its development was envisioned by the founder Sr. Frances Dominica and the parents of a little girl with a life limiting condition, called Helen. Helen lived at home with her family but required 24 hour care, and as a result her parents recognised the need for respite in a suitable environment. LauraLynn hospice, Ireland’s first children’s hospice opened its doors in 2011. The LauraLynn Children’s Hospice Foundation was established by Jane and Brendan McKenna, who had tragically lost both of their children, Laura and Lynn, to two different life limiting conditions in the space of two years. The LauraLynn Hospice Foundation project united with The Children’s Sunshine Home Hospice Project in order to take full advantage of their fundraising activities and fulfil their shared ambition of opening Ireland’s first children’s hospice.

Conclusion

Without doubt Ireland’s Paediatric Palliative Care service has been evolving in recent years as evident at the recent 2nd International Conference when Ms. Sheilagh Reaper-Reynolds, who is the national lead for palliative care in the Health Service Executive, gave a speech entitled, ‘From Policy to
Implementation – nurturing the growth of children’s palliative care to become a dynamic evolving specialty in its own right’ In this it was outlined how policy and implementation is fostering the evolution of children’s palliative care in its own right. She said “great progress has been made”. (Reaper-Reynolds, National Lead for Palliative Care in the HSE 2016)

Ireland has demonstrated its motivation and commitment to developing an excellent, equitable and accessible Children’s Palliative Care service for all children living with a life limiting condition. It is crucial for the service that we keep the momentum going. This is a consideration that will be looked at when future plans and recommendations are being discussed.
Chapter 3: Barriers to Paediatric Palliative Care

Introduction

Palliative Care for Children with Life Limiting Conditions in Ireland - A National Policy (2009) recommends that palliative care should be available for all children diagnosed with a life limiting condition. It states that, ‘Palliative care services for children should be accessible, equitable, flexible and appropriate and should meet the needs of any child with a life-limiting condition and their family.’ (DoHC 2009) However, time and again palliative care referrals come up against many barriers. Paediatric palliative care referrals are more contentious as palliative care continues to be viewed by many as end of life care, and as we all know, children are not supposed to die.

Families do not wish to be told that their child is in need of a palliative care service. The figures for Ireland as outlined in the previous chapter highlight the need for a PPC service. Given the often uncertain disease trajectory of the children diagnosed with LLC, ‘Parents whose child has survived against the odds may be reluctant to acknowledge an inevitably fatal outcome and often pursue desperate attempts to postpone it.’ (Davies et. al 2008)

What are the perceived barriers?

There are numerous barriers documented in the literature, however, for the purpose of this dissertation and clarity, the author will discuss the barriers in relation to the child, the family and to the healthcare professional. Recommendations to overcome these barriers will then be addressed.
Barriers which the Children may face

Unfortunately, there remains a stigma associated with the term palliative care. It is often viewed as ‘giving up’, or end of life care. Paediatric palliative care focuses on the quality of the child’s life no matter how long or short that may be. It aims to add quality to the lives of the child and family, and to support them to live their lives to their full potential, facilitating the child in leaving their mark on the world. ‘For parents who know that their child will soon die, hope may be fostered by helping to find meaning in their child’s life.’ (Liben et.al, 2008) The adults (both parents’ and healthcare professionals’) reluctance to refer the child to the palliative care service may negatively impact the child’s opinion of the palliative care team and interfere with their ability to build a relationship with the team. As stated by Harris (2003), ‘The word palliation carries the stigma of terminal care for patients, families and caregivers, when terminal care covers only a minority of children with cancer’, or indeed any life limiting condition.

The timing of a referral is of the utmost importance for the child to gain the most benefit from the palliative care service. Kaye et. al, (2016), states that, ‘The gradual process of building trust takes time and is best achieved during periods of stability and low stress.’ From the research however, it is evident that referrals tend to take place when there is a relapse of the condition or it is evident that the child is approaching the end of their life. Thompson et. al, (2009) concur with this when they say, ‘Our findings suggest that, despite recommendations to refer children to palliative care early in the course of illness, most paediatricians define palliative care as similar to hospice care and would make later referrals.’

An integrated model of care is most effective. Whilst the child continues to receive active treatment aimed at curing or controlling the disease or illness, the palliative care team are dealing with symptom management and building
a trusting relationship with the child. This will enable them to learn what the child’s wishes and values are thus leaving them in a position to improve the child’s overall quality of life. ‘Talking with them about their condition or plan of care allows healthcare professionals to find out what questions they have and what they are wondering about.’ (Rushton 2005) It also gains an insight into the child’s fears and their end of life wishes helping them to achieve their full potential in life. ‘Until palliative care can be perceived as support care that spans the spectrum of needs from diagnosis through to end of life care, early consistent referrals to palliative care will be difficult to implement.’ (Thompson et.al, 2009)

Children who have palliative care needs differ greatly from adults. They vary greatly in age and many have neurological conditions, all impacting their level of cognition. Children with palliative care needs range in age from neonates through to adolescents. Their understanding and emotional response to the situation will vary greatly as a result. ‘Developmental differences lead to physiologic issues such as different emotional reactions to the disease and its treatment and different levels of understanding regarding the disease process and its outcome.’ (Harris, 2003)

Effective, age appropriate communication with the child may therefore present as a barrier as children often feel as though they are not being heard or are not allowed to be actively involved in the decision making process around their treatment. This lack of communication often leads to fear as children are generally aware that something is amiss and realise that the adults are withholding information. There are effective ways of communicating with children and enabling them to have an influence in their own care. ‘These include (a) talking with them, (b) listening to them and responding to their concerns, (c) using appropriate techniques, for example, play to increase understanding and (d) acting in a way that demonstrates that account of their views has been taken.’ (Larcher et.al. 2015) Effective, sensitive sharing of information at the child’s pace will help to allay fears.
It is the family’s prerogative whether or not the child is included in the treatment plan, or is even aware of the diagnosis. Families often feel they are protecting the child by not disclosing this information, but it could be argued that it is the child’s information. If the child is not included, their wishes can only be presumed. This lack of communication also leads the child to fear the unknown. Children are imaginative and may concoct a very different illusion of their illness in their minds. ‘A common argument for direct communication with children and adolescents, however, is that not knowing can be more difficult than knowing, because uncertainty gives reign to one’s worst fears.’ (Mack and Joffe, 2014) Children may also be trying to protect their parents, by not initiating a conversation, as they know that discussing the gravity of their situation causes upset for their parents. Children should be provided with the opportunity to ask questions or discuss their fears on their own if necessary. As Mack and Joffe (2014) stated, ‘Like their parents, children often wish to protect their families from difficult conversations about the future.’

Barriers which the Family may encounter

When faced with a life limiting diagnosis the family’s world is turned upside down. Your job as a parent is to protect your child from harm. It is no surprise therefore, that a family may find it difficult to accept the healthcare professional’s terminal diagnosis. According to a study conducted by Davies et.al., (2008), ‘Given parents hopes and dreams for their children, it is understandable that the second most frequently reported barrier was the family not being ready to acknowledge an incurable condition.’ Denial can be a form of protection for the family as opposed to them not understanding the stark reality of the situation. It is communication again that may act as the barrier here. Healthcare professionals need to begin conversations early in the uncertain disease trajectory. This can benefit the family as the physician has the opportunity to allow the family to slowly digest the information and not expect them to make urgent end of life decisions. ‘... physicians who
face considerable prognostic uncertainty can begin conversations by using language that is open to multiple possible outcomes long before acute deteriorations necessitate urgent decision making.’ (Mack and Joffe, 2014)

At times, the parents may have a difference of opinion regarding a palliative care referral. One parent may be in denial of the terminal diagnosis and have an unrealistic hope for cure. This situation is very difficult requiring expert communication from the healthcare team. It is important for the child and family that they remain united in their decision making, with the hope that there will be no blame later in the course of the illness. ‘Uncertainty, if not dealt with openly, may undermine credibility and trust, may impede development of consensus among providers or between the health care team and parents...’ (Davies et.al, 2008)

The family may continue to pursue life saving treatments, and if not communicated with effectively, may not understand the role of integrated palliative care and the benefit it may offer to their child’s level of comfort and overall quality of life. The timing of a palliative care referral can be crucial to its acceptance. A discussion regarding the referral may often occur at a time of relapse, crisis, or when the child’s condition deteriorates. This may instil fear into the family and they may feel that the healthcare professional is ‘giving up’ on their child or that they are not being offered the best possible care. Davies et.al., (2008) again acknowledged this by saying, ‘The inability of providers to communicate clearly and sensitively about a child’s poor prognosis, along with their reluctance to dash all hope, may compound these parental perceptions.’

This highlights the importance of early referral, allowing the family to gradually adjust and realise the benefit of the role of the palliative care team. The family should never feel abandoned. However, the healthcare professional should never attempt to push the family into their way of thinking. It is about giving clear and accurate information to enable the family to make fully informed decisions. Mack and Joffe, (2014), stated, ‘...parents often want this prognostic information because it underpins informed
decision-making, especially near the end of life. In addition, despite understandable clinician concerns about its emotional impact, prognostic disclosure can actually support hope and peace of mind among parents struggling to live with a child’s illness.

Difference of opinion

Another barrier which the family may have to face is the difference of opinion with their healthcare team about the treatment plan for their child. We, as healthcare professionals should not force our own beliefs and assumptions on a family. Families’ different opinions, religious beliefs and cultures must be listened to and respected. ‘Offering care based on assumptions from their own personal and ethnic backgrounds, these healthcare professionals misunderstood the needs of children and families...’ (Liben et.al. 2008)

Healthcare professionals caring for children with a life limiting condition must be cognisant of differing family values, differing parenting techniques and differing levels of emotional reactions to these fatal diagnosis. Healthcare professionals must be aware of the emotional rollercoaster faced by families, who find themselves in these horrendous situations, and be prepared to support and empower them to make decisions appropriate to their individual child and family situations. As Himelstein et.al, (2004) stated; ‘...staff working with children who are facing a life-threatening illness and their families must possess fundamental knowledge and expertise in child development and family systems.

Barriers Facing the Healthcare professional

One of the main barriers which healthcare professionals report is an uncertain prognosis. This is one of the most challenging aspects of paediatric palliative care. Children present with rare, often undiagnosed conditions, so
the disease trajectory is impossible to predict. Healthcare professionals often continue to view palliative care as hospice or end of life care, therefore they may feel it is a ‘failure’ or that they are dashing parental hopes if they refer the child to palliative care services. Paediatric palliative care should be viewed as a support to the uncertainty, and to the healthcare professional in managing distressing symptoms and providing support for all the family. Davies et.al., (2008) remarked that ‘An uncertain prognosis should serve as a signal to initiate palliative care, rather than to avoid it, even when it is not yet appropriate to begin end of life care.’ Harris, (2003), concurred with this by saying, ‘The concept of quality of life should be introduced as soon as possible to the patient and family. The emphasis must be on addressing the physical, psychosocial, and spiritual needs of the patient and family to maintain as good a quality of life during treatment as possible.’

**Difficult decisions**

Medical advances have allowed physicians access to life saving/ life prolonging treatments and equipment that were previously not an option. This obviously has had huge benefits to people’s overall health but has also made for some very difficult decisions for healthcare professionals and families. Overly burdensome treatments may not be in the child’s best interest, but it can be difficult for the family and the healthcare professional to agree on this. A family may want every treatment option tried, and the healthcare professional will usually recognise when a treatment is becoming too burdensome on a child and having a negative impact on their quality of life. As Larcher et al., (2015) stated, ‘In this extraordinary world of medical miracles, one thing has not changed; the complexity, challenge and pain of that most difficult of decisions: is the treatment that we are providing no longer in the best interests of the child?’ They continue by saying ‘There is no technology to help us here- only guidance, discussion, and adequate time and information for truly shared decision making.’ This topic has huge ethical and legal dimensions and will be discussed further in a subsequent chapter.
Lack of experience

Lack of experience regarding symptom management and communication has been cited by healthcare professionals as major barriers also. A child dying is a relatively rare event, thankfully, but this does lead to inexperience. In a study carried out by Jünge et al. (2010) it was found that, ‘Education in basic palliative care competence and communication skills was seen as an important prerequisite for the engagement in paediatric palliative home care.’ In Ireland, palliative home care teams, which are primarily adult focused and have limited paediatric experience, are tasked with providing palliative and end of life care to children with life limiting conditions nationwide. They have the support of the paediatric palliative care consultant, as mentioned previously there is currently only one, via telephone, if specialist paediatric palliative care is required for the child. The child’s local healthcare provider should be in a position to assess the needs of the child and family and refer or consult with specialist services as required. ‘Primary care providers should be taught to recognise a child’s need for palliative care, to assess the emotional and spiritual needs of the child and family, to facilitate advance care planning, to assess and manage the child’s pain and symptoms, to provide bereavement care to the child’s family, and to recognise the indications for referral to a specialist.’ (Himelstein et al., 2004)

Geographical Location

As previously outlined, the numbers of children who require palliative care are relatively small; it therefore leads to a small cohort of suitably trained staff. This can be a barrier for families requiring a service, particularly in rural areas, as staff that have this level of specialised training tend to be placed in the larger acute hospitals. Price et al., (2015) alluded to this fact when they stated ‘Given that the numbers of children requiring a palliative approach to
care are much smaller than those within the adult population, the numbers of professionals providing the care are similarly fewer.’ This leads to families not being able to access a service depending on their geographical location.

The small numbers in Ireland has also meant that specialist sites for care are limited to the capital city. There is no hospice for children or specialist paediatric palliative care consultant in rural Ireland. Adult homecare teams and adult palliative care consultants are leading the care in consultation with the child’s general paediatrician and via telephone to the specialist sites if required. ‘Community palliative care teams throughout the Republic of Ireland (ROI) usually care for adult patients; however, their role also involves caring for children with palliative care needs when required.’ (Quinn and Bailey, 2011) Again this has ethical and legal implications in relation to the child’s right to healthcare and accessibility, which will be examined later. The children’s palliative care programme has begun to address this by recruiting children’s outreach nurses for children with life limiting conditions. These specialist nurses are based in the regional paediatric units and are given the task of coordinating the care of these children. According to the DoHC (2009), the aim for the Children’s Outreach nurses are as follows, ‘...based in Regional Children’s Units in hospitals throughout Ireland and would be supported clinically by a named locally based paediatrician with an interest in palliative care. Further clinical support would be provided nationally by the Consultant Paediatrician with a Special Interest in Paediatric Palliative Care and the wider network of Outreach Nurses nationally.’

**Recommendations**

When a family is given the devastating diagnosis of a life limiting condition for their child, hope may be all they have. ‘At times, people may hold beliefs that although seemingly discordant with each other, (e.g. The knowledge that one is about to die at the same time maintaining hope for a last-minute reprieve from death) could instead represent health coping.’ (Liben et.al, 2008)
The stigma associated with palliative care from the healthcare professionals’ point of view along with that of the family needs to be addressed. Education regarding the benefits of palliative care and its focus on quality of life for the child and family needs to be promoted at a national level. A study of the barriers carried out by Dahlberg et al. (2013) supported previous findings that misconceptions about palliative care continue to exist. They recommended, ‘All providers agreed that misconceptions about the purpose of palliative care abound and that patients and families need to be educated about this service.’

In some states in the US a change of name from palliative to ‘supportive’ care has been trialled. Late referrals are a barrier to the effectiveness of the service which palliative care can offer. Research carried out by Hui et al. (2015) showed promising results in relation to rebranding. They found that, ‘Encouragingly, the stigma associated with palliative care can partly be overcome by a simple change in the service name to “supportive care”, which was well received by many clinicians.’

By encouraging integrated care, as opposed to a sudden shift from curative care, children and families are more likely to both accept a palliative care referral and gain most benefit from their expertise. As MacDonnell-Yilmaz, (2015) stated, ‘Palliative care, however, can be applicable to patients early in the course of illness, in conjunction with therapies intended to prolong life, and can provide a platform for discussing families’ preferences long before end-of-life decisions need to be made.’

Education of healthcare professionals in relation to effective communication can help to overcome a lot of barriers experienced in relation to paediatric palliative care referrals. Communicating with families in relation to a fatal diagnosis and end of life decisions is extremely difficult. ‘These skills, especially techniques for effective communication in emotionally charged situations, need to formally enter the medical training curricula in both theory and practice.’ (MacDonnell-Yilmaz, 2015) This training will also facilitate professionals in communicating at an age appropriate level with the children and also those who are neurologically impaired.
By enhancing the communication skills of professionals it will enable them to engage in conversations regarding the treatment plan of the child with the family. Families often have differing opinions in the course of action to be taken. Through gentle ongoing communication professionals can assist families to see that sometimes the time the child has left may be better spent at home making memories as opposed to one last treatment which is not going to cure their precious child. ‘Through compassionate, sensitive conversations with family members, the team aims to define achievable goals that address all aspects of care, physical psychosocial, and spiritual, in a manner that provides the patient and the family with the highest possible quality of life.’ (Michelson and Steinhorn, 2007) This in essence is the philosophy of Paediatric Palliative Care.

Conclusion

‘Healthcare professionals attending to children facing life-threatening conditions must be willing and able to discuss the possibility of death, the potential for physical and emotional suffering, and the strategies for its prevention and treatment frankly.’ (Himelstein, et.al. 2004)

The overarching theme emerging from the literature in relation to barriers to paediatric palliative care referrals is communication. Effective and compassionate communication requires time. Early referrals will have a lasting impact on the relationship built between the child and family and the palliative care team. This is the key to optimal end of life care for children with palliative care needs. Education of healthcare professionals in relation to the benefit of palliative care, communication and symptom management needs further development. Education of the public in relation to de-stigmatising palliative care and promoting the benefits of the service is ongoing. McIlfatrick et.al, (2014), acknowledged this when they stated, ‘Modification of public perceptions of palliative care is central to improving knowledge of and access to services, empowering individuals and involving communities in palliative and end-of-life care.’
Chapter 4: Benefits of Paediatric Palliative Care

Introduction

Although as discussed, the barriers to Paediatric Palliative Care are considerable, the benefits of a palliative care service can have a profoundly positive impact on the quality of life for the child and their family, therefore, we as healthcare professionals need to strive to overcome these barriers. Adult palliative care is well known for its role in providing a level of comfort to the dying, facilitating choice for the place of death, where possible, and allowing families to spend their last moments together, it aims to control all symptoms and relieve suffering at the end of life. It offers bereavement support to families after their loved one has died. ‘Service providers are required to ensure that, when death is inevitable, every patient receives appropriate and timely end-of-life care, focused on comfort and dignity while avoiding futile and invasive interventions that prevent a peaceful death.’ (Kennedy et.al, 2013)

Here is where the greatest difference between adult palliative care and paediatric palliative care can be seen. Nicholl and Tracey, (2015) commented that, ‘Children’s and adult palliative care principles share similarities in that they are family focused and family involvement can be applied to both.’ Paediatric palliative care however, spans the entire life of the child diagnosed with a life limiting condition. It encompasses all developmental stages from a neonate through to adolescence, including children with neurodisabilities. It provides support for the child, family and their siblings from diagnosis right through death and to bereavement care. ‘Paediatric palliative care encompasses more than the final weeks to days of life, moving upstream to the long period of chronic complex care.’ (Siden et.al, 2014) Harris, (2003) stated, ‘traditional palliative care focuses on end-of-life care and not on improving the quality of life that the majority of children who survive require.’ In this chapter the author will verify the benefit of an early referral to paediatric palliative care for both the child and family, and the healthcare professionals caring for the child. The cost effectiveness of this
referral will be examined along with the benefits of a community based paediatric palliative care programme. In Ireland this has begun to take shape in the form of the Children’s Outreach Nurse service as part of the paediatric palliative care programme.

**Benefits of an Integrated Approach**

Early referral of children with a possible life limiting diagnosis allows for an integrated approach to care. This is where the child and family can actively pursue treatment alongside the input from the palliative care team. ‘By introducing the concept early in the illness, care of all symptoms experienced by these children can be more effectively and seamlessly managed.’ (Johnston et.al, 2008) Early referral allows for a trusting relationship to develop between the child and family and the palliative care team. This allows the team to gain insight into the values and goals of care for the child and family, thereby enabling them to advocate effectively for treatment options and place of care. ‘...it insists that a meaningful, interactive relationship among patient, family, and healthcare professionals provides the foundation for advocacy and treatment’. (Rushton, 2005) This model of care enables the child and family to pursue active treatment whilst any distressing symptoms are being managed simultaneously. The aim in essence is to maximise the quality of life for the child throughout the course of their illness. ‘This change in thinking emerged from a new understanding that problems at the end of life have their origins at an earlier time in the trajectory of disease.’ (Sepúlveda, 2002)

**Child Specific Plan**

The benefit of an early referral also allows the family and team to develop a child specific plan, and facilitates growth of a trusting relationship. Each child diagnosed with a life limiting condition is an individual, with very individual needs. As Weaver et.al, (2016) stated, ‘...a claimed uniqueness warranting
the specific attentiveness of care providers.’ A child with a life limiting illness 
may experience many ‘end-of-life’ events during their journey and will require 
a consistent level of support each time. This can be a hugely emotional 
experience for the family and the relationship with the team is dependent on 
that early referral as opposed to a referral in times of major stress. ‘Within an 
integrated model, uncertainty is a reality of the lived experience - not an 
impediment to moral agency.’ (Rushton, 2005) When a relationship with the 
palliative care team has been established, this continuity of care allows the 
team to establish the areas of greatest concern for the child and family. In 
this way the palliative care team are in a position to optimise the level of care 
the child and family receive throughout the course of the illness, which will 
have a lasting impact on the family’s coping after the death of their child. ‘By 
gathering more information about the home and family life and the child’s 
quality of life, the palliative care team identified critical areas where 
improvements could be made in symptom management, communication, or 
coordination of care services.’ (Walter et.al, 2013)

Benefits of Parallel Planning

Having the time to become familiar with the child and family in a non-
stressful environment enables the team to facilitate ongoing conversations 
around the notion of parallel planning. To have a conversation with a family 
about the possibility of the death of their child is a hugely emotional task for 
any healthcare professional. It has been frequently documented that 
healthcare professionals often avoid this conversation as they do not wish to 
upset the family. ‘Allowing the possibility of death to be acknowledged and 
any plan of treatment to be discussed realistically gives precious time for the 
patient and family to express their preferences. This facilitates an 
individualised plan of care, particularly where no restorative treatment is 
possible or further decline would herald the end of life.’ (Kennedy et.al, 2014) 
This is a conversation that needs to happen gradually and is most beneficial 
to the child and family when undertaken by a trusted healthcare professional. 
A healthcare professional who is competent and open in communicating at
this level with the child and family will have the ability to facilitate the family to come to a decision which best suits their needs and values, a phenomenon that is even more pronounced within an established relationship. In a study conducted by Walter et.al, (2013), they examined the benefits which families described from a palliative care consult. They found that, ‘Families were receptive to the palliative care team’s introduction of a framework for decision-making in which both the “benefits versus burdens” of medical interventions were evaluated.’ In this study it was also documented that, ‘The palliative care team also assisted in coming to a decision over particular interventions.’

Benefits of a Multidisciplinary Team Approach

Children and families with palliative care needs require input and support from a myriad of professionals. They have needs spanning from physical, psychosocial, to spiritual and religious. All healthcare professionals caring for children should be familiar with the palliative care approach and competent in communicating in a compassionate and age appropriate manner. ‘Effective communication among all parties from the patient and parent to the comprehensive care team (social workers, psychologists, child life specialists, and clinicians) is crucial to successfully capture the child’s/adolescent’s end of life preferences, including the practicalities of location of death.’ (Weaver et.al, 2015)

Healthcare, including paediatric palliative care is resource dependant. In Ireland, as in most other countries, there is insufficient specialist palliative care teams to provide a full service nationwide. That said, in the absence of complex symptoms, a patient’s palliative care needs should be able to be met by healthcare professionals, who have insight into the basic principles of palliative care. The National Clinical Programme for Palliative Care HSE, (2014) states, ‘All health and social care professionals working with people with life-limiting conditions are involved in providing palliative care.’ Palliative care is provided at a general level by all healthcare professionals.
Healthcare professionals should be in a position to assess when a consult from the specialist palliative care team is required to address the needs of the child and family, in combination with their generalists approach. Walter et.al, (2013), identified this by saying, ‘... it may be beneficial to many chronically ill patients to have generalists also learn the skills to address family’s understanding of prognosis, helping with complex communication situations, and assisting in decision-making about treatment options in patients of all ages and across disease courses.’ Specialist palliative care teams aim to support the child’s primary care team, and offer support and guidance in relation to symptom management and other psychosocial needs as identified and required. ‘In a coordinated palliative care model, the primary care physician or treating specialist could manage many palliative care problems, initiating a palliative care consultation for more complex or refractory problems.’ (Quill and Abernethy, 2013) This was again verified by Kaye et.al, (2016), when they stated, ‘In all instances, involvement of a palliative care team is meant as an extra layer of support, to collaborate with, not supplant, the primary oncology team.’

Improved coordination of care

As previously discussed, children with palliative care needs are a hugely diverse cohort of patients. There is a great variety of medical diagnosis; some are undiagnosed, all with different complex needs. Harrop and Edwards, (2013), described this when they said, ‘Specialist palliative care is provided to children with life-threatening or life-shortening conditions who have an extremely wide range of diagnoses (in excess of 300), and there is an overlap with those with severe disabilities and complex needs.’ Healthcare is a complex fragmented medical system. It can prove difficult for families; particularly very vulnerable ones, who have a child with a life limiting diagnosis to navigate.

Palliative care teams are often best placed to improve the coordination of care for these families, between acute and community settings and various
medical and surgical specialities. ‘Palliative care programs, because of their interdisciplinary approach, assist patients and families in understanding and regaining control over their care plans and in receiving further care in the setting most appropriate to their needs and resources.’ (Meier and McCormick, 2015) As children approach the end of their life they often have frequent, lengthy hospital admissions. In 2015 in Ireland, there were 59 recorded deaths of children with life limiting conditions under the care of the Children’s Outreach Nurse Service. Of these, 28, or 45.1%, died in the acute setting for a variety of reasons. Parental choice was cited as 46.4% of these. (Horne and Noonan, 2016) This figure is high considering the research shows that the preferred location of death is usually in the home. This is an important topic that will require research in the future. Did parents feel lack of support in taking their child home? Or perhaps, the complexity of the child’s symptoms determined that they were better controlled in the acute setting under the direct care of the paediatrician, as there was limited access to specialist palliative care service.

Palliative care consults can help both the family and the healthcare professional to deal with distressing symptoms and manage other stressors. Bringing a child home from hospital for end of life care can be an enormous task for the parents. They need to know that they will have access to specialist paediatric palliative care for control of their child’s symptoms if required. They also need to have sufficient support at home from healthcare team members who have expertise and experience in caring for children with palliative care needs. The palliative care team can assist in coordinating this care between the acute and community teams. ‘Teamwork can, and should, be the hallmark of effective palliative care.’ (Johnston, 2015) This can facilitate the child and family to be cared for in so far as possible in the comfortable surroundings of their own home. ‘Consistent with the goals of a majority of patients and their families, palliative care recipients spent less time in intensive care, were less likely to die in intensive care units, and were more likely to receive hospice referrals than the matched usual care patients.’ (Morrison et.al, 2011)
Cost Effectiveness of Paediatric Palliative Care

The health system is obviously extremely resource dependant, on both material and competent staff resources. Resource allocation can have major ethical implications in healthcare and will be discussed in a later chapter. ‘In the context of limited resources, evidence on costs and cost-effectiveness of alternative methods of delivering health-care services is increasingly important to facilitate appropriate resource allocation decisions.’ (Smith et.al, 2014) Due to a highly technical medical era with the increased use of life prolonging equipment and medication, paediatric palliative care is more beneficial than ever. Palliative care has been demonstrated to reduce the number of hospital admissions, reduce the level of aggressive ‘overly burdensome’ treatments at the end of life and help children and families achieve their goals of care, all of which proves to be cost effective on the health system. In a study, conducted in the USA, by Morrison et.al, (2011), they concluded that, ‘Our study expands and amplifies the results of prior studies by demonstrating that palliative care teams not limited to intensive care units can produce appropriate care matched to achievable patient and family goals, as well as savings, across hospital settings.’

Proof of Cost Effectiveness

Currently in the healthcare system, we are very aware that resources are not infinite. It becomes very important to personnel responsible for resource allocations to prove the cost effectiveness of a service and also ensuring value for money for the consumer. ‘...there is pressure to strengthen accountability for the quality of care at the end of life and achieve better outcomes with fewer resources.’ (Kassam et.al, 2014). There is numerous studies detailing the evidence that palliative care is indeed cost effective to the health system. Twenty-five percent of children did not visit the hospital outpatient department at all and 41.5% required no hospital admission during the palliative phase. (Vickers et al, 2007) This is a significant finding within
the UK, our closest neighbour, with a comparable geography and healthcare system. In a meta-review by May et.al, (2014), of eight published systematic reviews and one relevant non-systematic review, they examined literature on adult palliative care, within a US setting. Articles that were included were those that compared the costs and/or cost effectiveness of a specialist hospital inpatient palliative care consultation for adult patients with those of a comparator, it was concluded that, ‘The evidence now suggests that specialist inpatient palliative care both reduces costs and improves patient outcomes.’ Home based palliative care has also been shown to decrease health care costs.

A study, conducted throughout three Canadian provinces, although adult based, highlights again the cost-effectiveness of palliative care. ‘Those results confirmed our hypothesis: in all three provinces, an increase palliative homecare nursing was associated with an overall lower total cost, but only in the last month of life.’ (Seow et.al, 2016) Another Canadian adult focused study demonstrating these results was conducted by Cheung et.al, (2015), they concluded that ‘Costs are substantially higher for patients managed aggressively in the final weeks of life, and they are driven by a heavy dependence on acute institutional care.’ Owing to a paucity of research articles found, demonstrating the cost-effectiveness of PPC may be in part owed to the fact that PPC is a relatively new discipline; the need for further international research is required.

**Implications for Service**

It can be much more difficult to prove the cost effectiveness of paediatric palliative care. As it differs to the way in which adult palliative care is delivered at the end of life, the costing of paediatric palliative care can vary substantially depending on the local facilities, resources and the attitudes of the referring generalists. In the UK within which a similar care delivery system exists Vickers et al, (2007) describe how PPC is delivered in a paediatric oncology setting, and state ‘care is rarely hospice centred, but typically provided at home, with support from a hospital-based oncology
team. Liaising between oncology centres, primary healthcare team (PHCT) and family is the responsibility of the paediatric oncology outreach nurse specialist, (POONS).’ In Ireland the Childrens’ Outreach Nurse (CON) has been given the liaison role with the more extensive remit encompassing all children with life-limiting conditions. However studies based on the delivery of adult palliative care has found that by healthcare teams discussing patient’s end of life care, costs could be reduced. Patients may not wish for aggressive treatments if they are aware of the unlikely benefits. ‘Our findings demonstrate that patients with advanced cancer who reported End of Life (EoL) conversations with physicians had lower medical costs in their final week of life compared with those who did not, which is largely a function of their more limited use of intensive interventions.’ (Zhang et.al, 2009)

The ACT categories, which are the globally recognised groups of conditions identified as possibly requiring palliative care, can be ambiguous. There are certain conditions which the consultant may not see as life limited, or may not refer to palliative care as the child is still undergoing active treatment. The lead consultant may see such a referral as a failure on their part to treat the child. Therefore accurate data to plan for the costing of an economically sound paediatric palliative care service can prove extremely difficult. In the study carried out by Noyes et.al, (2013), they again referred to this when they stated, ‘The difficulty in establishing how many children need palliative care is further complicated by the fact that many key terms are not agreed among providers.’

Respite Care

Respite care is also included in the definition of paediatric palliative care. Respite care provides short breaks for the carers of children with palliative care or complex medical needs. This respite can be provided in the form of ‘in-home’ respite, community residential, ‘home-from-home’ or hospice. In Ireland, respite services are not equitable. What respite is available varies between regions. The only children’s hospice is based in Dublin, which therefore, makes it difficult for children at the other end of the country to
access respite breaks. In a systematic review of Organising palliative care for rural populations, Evans et al, (2003), postulates that palliative care services have developed mainly in urban areas due to higher population density that in turn facilitates specialist palliative care staff to work alongside generalist nursing and medical personnel. As already stated paediatric palliative care extends across the life of the child’s illness, encompassing many children with neurodisabilities. Children with long term chronic illnesses require a lot of care and support. It places pressure on the parents and families to provide this care as they wish to have their child at home and be included in family life.

Respite services for children with life-limiting conditions in Ireland, A Needs Assessment was published in 2013. It highlighted the need and benefit for a coordinated service. ‘A well-structured respite service can reduce hospital admissions; both because it provides the additional community supports that may prevent a child’s condition from deteriorating to the point where hospitalisation becomes necessary, and because many tests and procedures may be completed as part of a respite programme.’ This report also stated ‘Caring for a child with a life-limiting illness at home is potentially stressful for families. Respite care confers important benefits and is an essential component of a comprehensive children’s palliative care service.’ By assisting families in caring for their child in their chosen location, which is usually in the home, the cost of hospitalisation and overly burdensome treatments may be reduced. At a recent Irish conference on children’s palliative care leading health economist Professor Charles Normand-Edward Kennedy, Professor of Health Policy at Trinity College Dublin, argued that it can make economic sense for palliative care for children to be provided in the child’s own home. “Studies have shown that care in hospital tends to be much more expensive for these children and in most cases is less suitable. Shifting the balance towards support for people to remain at home achieves more at lower cost. It is hard to argue for doing less for more,” Professor Normand stated.
Benefits of a Community based Paediatric Palliative Care Service: In the Irish Context

Throughout the literature it is evident that the preferred location of care for a child with a life limiting condition is in the home. It is also the documented preferred location of death for both the child and family. However, in the Irish context it has been seen that the acute setting remains the main location for the death of a child, with almost half of the parents whose child died in hospital, citing this as their preferred location for the death. However studies (Bluebond-Langner et al, 2013, Siden et al, 2008 & Vickers, 2007) indicate that as the illness progresses and symptoms become more burdensome the actual location of death is less of an issue, than being involved in the EoL planning and symptom management of the child. Such planning is often facilitated by a community based paediatric palliative care team. When an early referral is made to the team a rapport is built and the team are then in a position to initiate these difficult conversations.

‘Once trust and relationships are securely established, Community Based Paediatric Palliative Care (CBPPC) providers also have an opportunity to provide context-specific anticipatory guidance, empower children and families to identify care goals, and formulate strategies to tailor management plans to their hopes and preferences.’ Kaye et.al, (2015)

Another area, in which the CON’s are involved, is the collection of national data in relation to children with life limiting conditions, and the deaths of these children. This data will be used for the future provision of resource allocation in caring for these children. ‘Community based nursing care has been identified as the essential bedrock of palliative care for children, providing families with a real choice about their child being cared for, or dying at home.’ (Downing et.al, 2012)
Conclusion

Paediatric Palliative Care has many documented benefits, with the overall quality of the child’s life in the centre of the family as priority. ‘Paediatric palliative care is not about dying, but rather about comfort and enhanced quality of life for the child.’ (Hill and Coyne, 2012) PPC should be introduced early in the course of the child's illness to gain acceptance and for the child and family to gain maximum benefit. ‘To have a meaningful effect on patients' quality of life and end-of-life care, palliative care services must be provided earlier in the course of the disease.’ (Temel et.al, 2010)

The palliative care team can address the multiple symptoms which a child with a life limiting illness experiences. If a child is less symptomatic, and receiving the care they require in their chosen location, the benefits are boundless. Temel et.al, (2010) stated that ‘Less aggressive end-of-life care did not adversely affect survival. Rather, patients receiving early palliative care, as compared with those receiving standard care alone, had improved survival.’ Although this study is based on findings from an adult population, it is likely, as with other studies from a palliative care perspective that the findings will crossover to the paediatric cohort.

Resources to provide an adequate, equitable service are not easy to justify. We need further data on children with palliative care needs, and the cost effectiveness of such a service in Ireland. As the service builds, research will be embedded within the speciality to demonstrate benefits and strengthen the case of further development of this specialist area. ‘Once trust and relationships are securely established, Community Based Paediatric Palliative Care (CBPPC) providers also have an opportunity to provide context-specific anticipatory guidance, empower children and families to identify care goals, and formulate strategies to tailor management plans to their hopes and preferences.’ (Kaye et.al, 2015) We have made progress and are continuing to strive for an optimal, achievable paediatric palliative care service throughout the country.
Chapter 5: Legal Issues in relation to Paediatric Palliative Care in Ireland

Introduction

This is the year of the centenary of the Easter Rising in Irish history. The 1916 proclamation has been read numerous times throughout the country over the last few months. There is one line in the proclamation that captures the attention of those working with vulnerable children. ‘The Republic guarantees religious and civil liberty, equal rights and equal opportunities of all its citizens, and declares its resolve to pursue the happiness and prosperity of the whole nation and of all its parts, cherishing all the children of the nation equally...’

When working with or caring for children, many legal aspects play a role in ensuring their safety or protecting their rights. Children’s rights within the family and their own individual rights have been recognised and protected within the Irish constitution since 1992, when Ireland ratified the UN Convention on the Rights of the Child. The legal aspects in relation to a child receiving palliative care are numerous and can be complex. Those that will be discussed in this dissertation are the ones that we, as healthcare professionals, encounter most frequently and which play the greatest role in guiding decision making when providing palliative care to a child. The topics which will be examined are; the child’s right to healthcare, family’s rights, consent, and the best interests of a child, withholding and withdrawing of life sustaining treatment, advance care planning and research in relation to children with a life limiting condition. The rights of the unborn child and the issue of abortion in Ireland will also be addressed, as this perhaps leads to a greater number of neonates being born with congenital abnormalities, and thus requiring palliative care. All of these topics are extremely emotive and at times there is a difference of opinion between the child and family or the healthcare professional, and the advice of the courts must be sought. Ethics around these topics also plays a major role and will be discussed in the next chapter.
Right to Health

‘Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services...’ (Article 25, Universal Declaration on Human Rights)

Everyone living in Ireland, including children has a right to health and it is the responsibility of the Irish Government to protect and to deliver that right. It is important to state that there is a difference between being healthy and a right to health. The Irish Government cannot prevent illness, but they are obliged to provide services, equipment and conditions that promote good health. ‘In 1966, Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) made the right to health legally binding, when it said that every country signing the Covenant should recognise ‘the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.’ Ireland ratified this Covenant in 1989’ Amnesty International.

Ireland ratified the UN Convention on the Rights of the Child in 1992. Article 24 states, ‘The child has the right to the enjoyment of the highest possible standard of health and to have access to healthcare and medical services. In its provision of health services, the State shall place special emphasis on primary and preventative health care and public health education.’ As demonstrated throughout the dissertation, paediatric palliative care promotes the health and quality of life of children with a life limiting condition. It can therefore be argued that children should have the ‘right’ to access palliative care and that it should be offered and promoted at the time of diagnosis in order to gain maximum benefit. Perhaps in order to promote early referral to the service in Ireland there needs to be legislative component, tying a referral to the time of diagnosis as has been implemented in Germany, since April 2007 the social legislation anchors in law the individual right to specialist palliative home care. (Jünger et.al, 2010)

Germany was the first country to have laws concerning palliative care. In 2007 a new paragraph was added into the Social Code Book V, entitling
patients including children, to outpatient specialist palliative care. This reform intended to strike a balance between the need for reform and the commitment to safeguard universal access to essential health care regardless of the ability to pay. ‘The reforms will increase the level of equity since every individual will have a guaranteed right to health insurance.’ Lisac, (2006) Brueckner et al (2009) state that, while this legislative framework has made steps to improve the service, it has also led to problems in the form of ‘Interdisciplinary rivalry and strong lobbyism have increasingly invaded palliative care now that it has become a new specialty requiring appropriate funding from the statutory health insurance system’.

Rights of the Family

‘The State recognises the Family as the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law.’ (Article 41 of the Constitution of Ireland) The child is embedded in the family unit. When caring for a child one of the basic concepts of all healthcare professionals is that the child and family are to be cared for using a family centred approach. This is heightened when there is a child who is life limited. The family’s instinct to surround and protect the child becomes evident. As Jünger et.al., (2010) described it by saying, ‘The situation of a family with a severely ill child or adolescent is typically characterised by an interaction of emotional distress, social isolation due to feelings of shame or insecurity on part of the environment, practical challenges in the organisation of care and a social/existential emergency. Therefore, it is important to consider the whole family system in order to meet the complexity of the situation.’

The emphasis placed on the value of the rights of the family is evident when the healthcare professional and the parents disagree on a course of care. Most often disagreements can be resolved with exquisite communication. Families in these situations are vulnerable and frightened but with comprehensive explanations regarding their child’s illness, prognosis and
end of life care, most treatment options can be made in partnership with the families. Research carried out by Enguidanos et.al. (2014) on family members perceptions of a palliative care consult found that, ‘Receipt and consistency of information and clear discussion of care options were aspects of the consult that impacted family member decision making’. However, when agreements cannot be reached, and one or other of the parties are concerned about the child’s welfare, the courts are asked to intervene. ‘On rare occasions the best care plan for a child will need to be decided in court.’(Wolff et.al. 2011) When this happens the court will assess using the child’s ‘best interest’ principle.

**Best Interests of the Child**

In Ireland in 2012, the State voted for amendments to be made to the constitution giving more clarity and stance to children’s rights. The new amendment officially lay down that children’s best interests shall be of the utmost importance when critical decisions are being made about the protection, welfare and care of the child. Article 42A, 2.1 states that;

‘In exceptional cases, where the parents, regardless of their marital status, fail in their duty towards their children to such extent that the safety or welfare of any of their children is likely to be prejudicially affected, the State as guardian of the common good shall, by proportionate means as provided by law, endeavour to supply the place of the parents, but always with due regard for the natural and imprescriptible rights of the child.’

This reflects the fact that the courts do not wish to override the family unit unless it is considered absolutely necessary. The Constitution also states in article 42. 4. 1,

‘Provision shall be made by law that in the resolution of all proceedings – i) brought by the State, as guardian of the common good, for the purpose of preventing the safety and welfare of any child from being prejudicially affected, or ii) concerning the adoption, guardianship or custody of, or access to, any child, the best interests of the child shall be the paramount consideration.’

This section of the amendment is very important; it commits the Oireachtas to legislate to ensure that the best interests of the child will be “the
paramount consideration”, in certain areas of decision-making affecting a child. This means that all decisions concerning the child will be determined with their best interests to the fore. In relation to a child with palliative care needs this is particularly relevant when it becomes evident to the healthcare professional treating the child that the treatment is no longer beneficial, that it is having a negative effect on their quality of life. Decisions regarding treatment options for a child or decisions to forego treatments are always best made with open, honest communication and in partnership with the child and family where possible. Healthcare professionals will only seek the advice of the courts if there is conflict around the best interests of the child, and fear that the treatment is overly burdensome and not in the child’s best interest, when the parents are requesting it, or perhaps that there is a treatment which should be trialed but the parents are not in favour of it. The State is bound under legislation of ‘The Child Care Act’ 1991, to intervene to protect children where required if it is carefully assessed and decided that the child’s parents have failed in their duty to the child. Healthcare professionals wish for the best outcome for the child and family. These situations are extremely challenging for all parties involved. ‘Doctors also want guidance that seems to them to be intuitively correct and consistent with what they understand to be the core purposes of medicine.’ (Sommerville, 2003)

The best interest test, whilst in theory appears to be the best approach in deciding treatment options for a child who does not have the capacity to make the decisions for themselves, is subjective. It is based on what the person deciding thinks is best for the child. A range of factors are taken into account, including age, religion, culture etc., however only the child’s interests are considered. ‘As factors included in the test depend on the subjective view of the decision maker, it is not objective.’ (Inwald, 2008) Whilst this may be the best approach when making decisions in relation to neglect or abuse of the child, perhaps in decision making regarding the end of a child’s life, the family’s interests as a whole should be assessed, as it will ultimately affect all members. Inwald, (2008), argued that, ‘an approach which recognises that the interests of a young child are difficult to separate entirely from the interests of other close family members and that in end of
life decisions the quality of life of that child can be properly understood in the context of his family.'

Consent

According to the Irish National Consent Policy, 2014, ‘It is a basic rule at common law that consent must be obtained for medical examination, treatment, service or investigation.’ Genuine informed consent is difficult if not impossible to obtain if all contributing factors are to be adhered to. According to El-Wakeel et.al., (2006), ‘A truly informed consent requires full disclosure of all relevant information by the doctor, competence of the patient to appreciate what the information signifies, understanding of the facts and issues by the patient and a voluntary non-coerced choice by the patient leading to an autonomous authorisation for treatment.’ The need for consent is recognised in Irish and international law.

Consent in relation to minors who are considered to lack capacity is even more complicated. Parents, in the eyes of the law, have the right to give consent, or refusal to medical treatment on behalf of their child. As already discussed, this is only questioned when the child or the healthcare professional are not in agreement with the parent’s choice.

In Irish law ‘the age of majority is 18 years, or the time of marriage if this is at a younger age (Age of Majority Act 1985). Irish law recognises that one becomes an adult for the purposes of consent to medical and surgical treatment at the age of 16 (Non-Fatal Offences against the Person Act, 1997 Section 23’ (Ni Riain, 2005). The Child Care Act 1991, the Children Act 2001 and the Mental Health Act 2001 define a “child” as a service user under the age of 18 years, “other than a service user who is or has been married”. The law however, has not made a significant statement in relation to an adolescent of 16 or 17 years refusing life sustaining medical treatment, when this decision is not in agreement with the parents. Article 42A.4.2 states that, ‘... in respect of any child who is capable of forming his or her own views, the views of the child shall be ascertained and given due weight having regard to
the age and maturity of the child.’ Children may not have the capacity to consent to medical treatment; however they have the right to be informed and express their views. This ensures that if a case goes to the courts for a decision that the child’s opinion will be heard. However this is much more difficult to ensure out of the legal system, as at times, parents do not wish to include the child in decision making. The amount of information which the child is given in relation to their illness is dictated by the parents. This is understandable, as a parent wishes to protect their child, but open communication, taking the cue from the child should be encouraged. ‘A safe environment, be it at home, in a hospice or in hospital, where the emphasis is on truthfulness, needs to be established at diagnosis and continued throughout the illness journey.’ (Dunlop 2008).

‘In many jurisdictions a minor is capable of giving informed consent when he or she achieves a sufficient understanding and intelligence to enable him/her to understand fully what is proposed.’ (HSE, 2014) The Gillick standard, introduced from a case in the House of Lords in the UK in 1985, initiated a legal assessment of the capacity of a minor to consent without the knowledge of their parents. It states, ‘... as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed.’ In other words, the ruling allows a minor to give consent to medical treatment, if he/she is capable of understanding the consequences of the decision in question. This is important for children with life limiting conditions, many of whom have been undergoing medical assessment and treatments for years. They have vast experience of the medical world and it can be argued that many have the knowledge and experience required to be assessed as having the capacity to consent or refuse treatment.

Children with disabilities should be given information in a manner which they can comprehend. Again their views and opinions should be heard and given due weight in accordance with their age and level of understanding.
Withdrawing/ Withholding of Life Sustaining Treatment

‘The capacity to prolong life beyond the point at which it may be perceived to have benefit or meaning to the individual (or to those around them) has forced us to examine difficult questions regarding human identity, personhood, rights and responsibilities with regard to access to medical care, the goals of health care and the very manner of our living and dying.’ (Moore et.al. 2008) These decisions are extremely difficult for all concerned, the healthcare professional, the child and family and extended family. The decisions have major ethical components which will be explored in a later chapter. There is also a legal basis to guide the decision makers. ‘These are based on the present and future ‘quality of life’, ‘futility’ of present treatment and a comparison of ‘burdens versus benefits’ of present and future treatment and its discontinuance.’ (Tiballs, 2007)

The legal aspects should be based on open communication, and shared decision making with the parents and child if appropriate. The Medical Council of Ireland states that, ‘there is no obligation on you to start or continue treatment, including resuscitation, or provide nutrition and hydration by medical intervention, if you judge that the treatment: is unlikely to work; or might cause the patient more harm than benefit; or is likely to cause the patient pain, discomfort or distress that will outweigh the benefits it may bring.’ Most of these decisions are made in cooperation between the parents and the healthcare team. Very few of these cases require the interference of the courts. ‘Decisions to limit treatments—or what treatments should be given—should be made by clinical teams in partnership with, and with the agreement of, the parents and child (if appropriate). They should be based on shared knowledge and mutual respect.’ (Larcher et.al. 2015)

If required to intervene the courts will examine and make decisions on each individual case in its own right. In Ireland there is an inherently strong obligation to protect the right to life. However, if it is in the child’s best interest to withdraw or withhold life sustaining treatment which would be ‘inflicting inhuman and degrading treatment’ (Article 3, UN Convention on the Rights of
the Child), this obligation can be overridden. Again particular regard must be given to the child’s opinion as appropriate in relation to what course of action is in their best interest.

**Advance Care Planning**

Studies have shown that it is likely that a child is aware when their death is imminent. In a study conducted by Slaughter and Griffiths, (2007) examining children’s concept of death they found that, ‘Our results show that once children begin to conceptualize death in biological terms, in the preschool and early school age period, there is also a decrease in their fear of death.’ The study also explored children’s fear of death. They deduced that, ‘It is not yet clear whether reduction of fear of death would be even more pronounced once children mastered all five subcomponents of the death concept, which usually occurs around age 10.’

Healthcare professionals should respond to cues from the child as to how much information they want and how much they wish to be involved in the decisions surrounding their end of life care. ‘During sensitive discussions, the child may reveal that they are aware of their impending death, yet may not want to discuss this further.’ (Dunlop, 2008) The right of the child to have their opinion heard in relation to all matters concerning them is at play here. The values of the family’s rights are considered by the healthcare professional, and if necessary by the legal body, also. It is important for healthcare professionals caring for children with life limiting conditions and their families to be open to discussions regarding the child’s end of life care. This is fundamental in promoting the quality of life for the child and family. Himelstein et.al, (2004), characterises this by saying, ‘Health care professionals attending to children facing life-threatening conditions must be willing and able to discuss the possibility of death, the potential for physical and emotional suffering, and the strategies for its prevention and treatment.’

The aim of the discussion with the family to plan for the child’s end of life care is to offer them a choice. Choices can be offered in relation to the
preferred location of death, the level of support they require from the team, and also the decision to limit certain treatments, such as cardiac resuscitation which may cause distress without benefit to the child. ‘Do-not-resuscitate (DNR) orders were developed as a means of inducing an informed decision by the patient, or the patient’s health care proxy, on what procedures would not be implemented at the time of cardiac arrest.’ (Sanderson et.al. 2013) Most healthcare bodies have moved away from the negative connotation regarding DNR orders. For children with a life limiting condition an advance care plan, constructed in conjunction with the child, family and healthcare professional is best practice. ‘Some hospitals have moved away from such binary negative type ‘orders’ to focus on more positive aspects of care which might appropriately be provided for children in these difficult circumstances, in the form of end-of-life care plans or pathways or advanced care plans.’ (Larcher et.al. 2015) ‘Confusion may arise if treatment preferences are not known but rather inferred from a DNR order.’ (Sanderson et.al. 2013)

One of the aims of the Children’s Outreach Nurse service is to introduce unified documentation nationwide for all children with life limiting conditions. An Advanced Care Plan which will now be used in conjunction with an ambulance directive and is currently being rolled out nationally. (Appendix 1) These documents will highlight the preferences of the child and family in relation to treatment options, including cardio-pulmonary resuscitation in the event of the child’s medical deterioration.

‘For incompetent adults and children, decisions are made by a surrogate.’ (McGowan, 2011) Parents, in the case of the child are usually best placed to make the decision on behalf of the child, in consultation with the healthcare professional, using the child’s ‘best interest’ principle. ‘When issues of medical futility occur, attempts to work with patients and their families should be undertaken, but if the dispute cannot be resolved, a transfer in care may be the only option.’ (McGowan, 2011) Open communication from the time of diagnosis is essential. The healthcare
professional and team must be objective when making professional
decisions regarding best treatment options for a child whose death is
imminent. Again, McGowan, (2011) highlighted this by saying, ‘This
standard is considered an objective standard because it does not rely on
imagining what the patient would chose, but rather on weighing benefits and
burdens of a proposed intervention or treatment.’

In Ireland advance care plans do not have a legally binding status at this
time. Advance care plans are very useful in initiating a discussion with the
child and family to learn what their wishes and fears are. It allows the
healthcare professional to discuss symptoms and possibly what to expect at
the end of life. It allows for the family to have a plan so that they feel
empowered to care for their child. However, the decisions made and
documented on these forms can be overridden at any stage if it is in the ‘best
interest’ of the child to do so. ‘Legislations in most countries reserve the right
to complete legally binding ADs to adults. Nevertheless, an AD/POLST
completed by a minor has notable weight in decision-making because it
gives strong indications on the patient’s presumed will’ (Lotz et.al. 2015)

In 2008 the HSE launched the National Strategy for Service User
Involvement in the Irish Health Service 2008-2013. This states that the
patient should be empowered to become an expert in their own care. It also
highlights the involvement of children. ‘All involvement work must make
specific efforts to ensure the participation of children, young people and
socially excluded groups.’ (DoHC and Executive 2008) ‘In paediatrics,
shared decision-making and planning of future care around the end of life
(EOL) may be challenged by prognostic uncertainty, the high emotional
impact of EOL decisions in children, the involvement of many different
parties in the care of children (parents, school), the importance for children to
maintain age-appropriate daily activities as well as the incapacity to consent
of many patients and the uncertain legal status of ACP documents by (or on
behalf of) minors.’ (Lotz et.al. 2015)
Research in Children's Palliative Care in Ireland

Research in any field is very important. It guides practice, identifies systems of healthcare which are not useful or cost effective and it provides evidence to ensure that effective services for children are designed, implemented and evaluated. Research is very important to ensure that we, in Ireland, are keeping up to date in best practice when caring for children with palliative care needs. ‘Research to improve health and decrease suffering of these significant and high-risk populations’ are critical, but recruitment challenges serve as potential threats to such studies.’ (Akard et.al. 2014)

It is the obligation of researchers and those reviewing research to protect the rights and welfare of the children involved in research. In April 2012 the Department of Children and Youth affairs launched, ‘Guidance for Developing Ethical Research projects involving children.’ In this document the rights of children in Ireland in relation to their participation in research are outlined. It states that children are protected by the United Nations Convention on the Rights of the Child (UN, 1989), which as previously stated Ireland ratified in 1992. Children who are capable of forming their own opinions as highlighted in Articles 12 and 13, have the right to express said opinions and to be heard. Children also have the right to access appropriate information as outlined in Article 17. Information must be given to the children and families pertaining to the fact that whilst they may not directly benefit from the proposed research it will hopefully benefit the treatment options of children in the future. The document also states that, ‘Although parental rights are given predominance in the 1937 Constitution of Ireland (Article 42), young people also have rights under Article 40.3.1, which include a right to dignity, privacy, bodily integrity and a right to autonomy or self-determination.’ It highlights that whilst these rights are not expressly mentioned in the text of the Constitution, but they have been interpreted by the Irish Supreme Court as falling within the meaning of personal rights in Article 40.3.
Children with chronic illness are very protected by their parents and the healthcare professionals caring for them. Researchers may find obtaining access to these children difficult as their parents may act as gatekeepers. Research teams need to inform families of the benefits open to them and the long-term benefits to help other families facing the same challenges they have. This must be done in an ethical way, not coercing the child or family. These issues will be discussed in the subsequent chapter. ‘Recruiters can help potential participants realize their opportunity to help other bereaved family members in the future.’ (Foster Akard et.al. 2014)

**Abortion and the Law in Ireland**

Abortion is a necessary topic to cover in relation to paediatric palliative care as; in Ireland members of society are currently in turmoil regarding the laws pertaining to abortion. Foetal anomalies are some of the main conditions in which neonates require the attention of the palliative care team. There are a higher number of children in Ireland with severe disabilities as a result of the lack of choice of the mother to terminate a pregnancy in which a major disability has been diagnosed antenatally. ‘The inability of service providers to effectively handle sensitive issues such as the termination of pregnancy (TOP) can result in enormous prolonged suffering for both the parents and the affected children.’ (Al-Matary and Ali, 2014) In Ireland there has been a continuous debate on abortion, and the laws have evolved only marginally over the last few decades. ‘Major congenital anomaly was the main cause of perinatal death, accounting for 26% of stillbirths, 48% of early neonatal deaths and 38% of late neonatal deaths.’ (Perinatal Mortality in Ireland, 2013) In the UK, ‘Congenital anomalies accounted for 32% of all post-neonatal deaths and 27% of all neonatal deaths’ (Office for National Statistics, 2013).

The outcome for neonates with fatal anomalies is not in question. Some of the foetuses do not survive pregnancy or childbirth. The neonates with anomalies which do survive may live for minutes, hours, weeks to months.
Infants may be born with major disabilities and due to medical technological advancement, such as artificial feeding and hydration, now survive for years. In these cases paediatric palliative care is essential. ‘There have been few reports concerning mode of dying from countries with low rates of termination of pregnancy, such as Ireland, where congenital malformations may account for a relatively greater proportion of neonatal deaths.’ (Finn et al. 2014) In June 2016 a complaint was made to the United Nations Human Rights Committee (UNHRC) against the Irish State in relation to its laws on abortion, ‘the UNHRC finds that Ireland’s abortion laws violated Ms Mellet’s right to freedom from cruel, inhuman or degrading treatment, as well as her right to privacy. The ruling also finds that Ireland’s abortion laws constitute discrimination against women on grounds of sex and denies them equal protection of the law.’ (Irish Family Planning Association, 2016) The debate in relation to abortion in Ireland has major ethical implications for these mothers and babies, and will be discussed later. An overview of the legal timeline will now be shown.

**Legal Timeline**

The 1861 Offences Against the Person Act, criminalised women who “procure a miscarriage”. The Act also criminalised anyone who assisted a woman to “procure a miscarriage”. Life imprisonment was the punishment in both cases. The Irish Statute books carried these laws for over 150 years with some amendments made to the Constitution. However, the 1861 Act remained the law on abortion in Ireland until the Protection of Life During Pregnancy Act 2013 was passed.

The 1861 Act also criminalised anyone who attempted to provide means to a woman to “procure a miscarriage”. In 1995, The Regulation of Information (Services outside the State for the Termination of Pregancies) Act was enacted. This allowed for information to be given to women on abortion services abroad should they seek it. The Act however had stipulations. The information was only permitted to be given in conjunction with counselling and with information on adoption and parenting. It prohibited doctors or other
President Michael D. Higgins signed the Protection of Life During Pregnancy Act into law in 2013. This Act allows a pregnant woman to seek lawful access to abortion where her life is considered to be at risk. If in the event she opts for an abortion in any other circumstance she must travel out of the State.

The Department of Health and Children has just issued its second annual report on the Protection of Life During Pregnancy Act to the Oireachtas. It covers the entire year of 2015. ‘The report shows that 26 medical procedures were carried out under the Act, 14 arising from a risk of physical illness, 3 arising from a risk from suicide and 9 from emergencies arising from physical illness.’

In a study conducted within an Irish maternity unit in 2014, it was found that, ‘Congenital abnormalities were the most frequent cause of death, accounting for approximately one half (47%) of overall deaths in our centre.’ (Finn et.al. 2014) If the law changes, women may be permitted to opt for an abortion in the case of fatal foetal abnormality. Fatal foetal abnormality and its diagnosis should be nailed down before being signed into law as its definition is variable in the medical field. ‘There is no agreement on the probability of death that would justify describing a condition as ‘lethal’.’ (Wilkinson, 2014)

Conclusion

All of these issues are particularly relevant in the legal context when discussing paediatric palliative care. Children’s rights are protected in the Constitution, but the children who require palliative care are especially vulnerable. ‘...it is especially important that decisions about end of life care are carefully thought through, with the best interests of the child at the forefront of this decision-making process.’ (Heckford and Beringer, 2014)

Most decisions concerning treatment options, palliative care and end of life care can be made in cooperation between the child and family and the healthcare professional. However on rare occasions, when there is a
disagreement that cannot be surpassed the courts are elected to intervene. McGowan, (2011) addressed this by saying; ‘However, in the absence of consensus, or perhaps a consequence of advances in medical technology, some of the difficult end-of-life questions have been brought to the courts for resolution.’ One such case that highlights these difficult issues where the courts are asked to intervene is that of Charlotte Wyatt, whose story will be outlined in a case study.
Chapter 6: Ethical Issues in Paediatric Palliative Care in Ireland

Introduction

With the advancement of medical, technical and pharmacological interventions, death at home is no longer a familiar event. There are many more treatment options available to patients and due to social media and the World Wide Web; people have more knowledge of treatments available. Death regularly occurs under the bright lights of an Intensive Care Unit (ICU). It is quite often seen as a failure to cure, an event to be feared. Rigorous treatments aimed at cure may be offered to patients until the terminal phase of their life. Currently in healthcare, ethics plays a major role, as patients are more autonomous and there are more treatment decisions to be made. In Ireland this has been supported by the HSE with their publication promoting the “expert patient”, in the’ National Strategy for Service User Involvement in the Irish health service 2008-2013’, Department of Health and Children Executive. Ethical decision making in healthcare is practiced on a daily basis. ‘Many facets of contemporary society are challenging the healthcare arena and demand constant reflection about the best professional attitudes to be taken in a diversity of circumstances.’ (Guedert and Grosseman, 2012)

‘The law or code of medical ethics must be understood as the moral navigation chart of medicine practitioners, as what it is aimed with is to help them not to get lost during the course of their work, pointing them out the right way to act with their patients and the community.’ (Sanchez Torres, 2015). Ethics is based on moral values. It guides healthcare practitioners, from medical, nursing, social work and all team members in their care of their patients at all times. As Sommerville (2003), described it ‘Practical problem solving involves verifying the facts in as accurate a manner as possible
before weighing up the different values and interests to reach an acceptable balance.’ Why are ethics so important in healthcare? Ethics allows for moral reasoning to be established in the face of dilemmas, and are entwined with the legal standing of the State.

In palliative care there are many dilemmas which the child, family and healthcare team face. The dilemma begins from the time of diagnosis of a potentially life threatening condition, to treatment options, when to introduce palliative care and when to withdraw burdensome, life prolonging treatments. The ethical dilemmas continue through to end of life care, incorporating palliative sedation and end of life discussions incorporating advance care plans. ‘Application of palliative care principles should guide communication about goals of care, and family education is of paramount importance to avoid possibly unwanted, futile, and burdensome interventions.’ (Arcand, 2015)

All of these dilemmas are exponentially more difficult when children are the patients. ‘Some of the most challenging and morally driven decisions in paediatrics involve end-of-life decisions, particularly decisions regarding the use of aggressive, potentially life-prolonging but burdensome therapies.’ (Michelson and Steinhorn, 2007) Ethical decisions involving children are extremely challenging as there is a triad of stakeholders, the child, the family and the healthcare team

For the purpose of this assignment, the ethical components of paediatric palliative care will be addressed under the four principles approach, or “Principalism”; Respect for Autonomy, Beneficence, Nonmaleficence and Justice as the basic moral principles as outlined by widely recognised bioethicists Beauchamp and Childress.

**Respect for Autonomy**

Adults, who are considered to have capacity, are recognised as being autonomous. They are capable of making decisions and judgements based on their moral principles and values. An autonomous decision refers to one which is informed, made without influence and the consequences of which
are understood. ‘The autonomous individual acts freely in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and establishes its policies’ (Beauchamp and Childress 2009). As previously discussed, in the eyes of the law an autonomous adult has the right to consent or to refuse any treatment offered, even if it is to their own detriment.

**Respect for Parental Autonomy**

When a child is the patient, the law recognises parental authority in relation to decision making. As outlined previously, this is rarely questioned as parents most often act in the best interests of their child. In order to support parental autonomy, effective communication and information sharing is essential. It is the duty of the healthcare professional to empower the parents of the child by offering them all the relevant information they require to make autonomous decisions on behalf of their child. Beauchamp and Childress, (pp103. 2009), gave a descriptive account of this when they said, ‘Respect, in this account, involves acknowledging the value and decision-making rights of persons and enabling them to act autonomously...’

Whilst honest information in relation to a child’s diagnosis and life limiting prognosis may be distressing for the parents and child, it is imperative that this information is imparted by the healthcare professional. Mack and Joffe, (2014), explained its value to parental autonomy by saying, ‘Conversations about prognosis thus support patient autonomy and value-driven decision-making, not just one kind of care.’

‘We all recognise that rights of parental autonomy often appropriately prevent governments from intervening in the rearing of a child.’ (Beauchamp, 2003) Parents, both ethically and legally are obliged to make decisions in the best interests of their child. At times their decisions may be in conflict with the healthcare team caring for their child. This can lead to ethical dilemmas between respect for autonomy and paternalism. ‘In many areas of medicine, the compassionate inclination helps us to uphold the fiduciary nature of the patient-physician relationship’. (Mack and Joffe, 2014) When a difference of
opinion occurs in relation to which treatment options are considered to be in the child’s best interest, the healthcare professional is obliged by law to put the child’s best interests before respect for the parent’s autonomy. ‘Clinicians have the fiduciary responsibility to protect the child’s best interests while also respecting familial autonomy.’ (Johnson et.al. 2015)

‘In evaluating parental decision-making, it is important for providers to understand that parents may weigh issues that differ from those considered by the clinician, or may give issues different weight.’ Johnson et.al, (2015) This statement is important to consider when ethical decisions must be made in relation to withdrawal or withholding of potentially life prolonging treatments. Parents have an enormous burden when making these decisions. They value the input of experience from their healthcare professional, but it should not be relayed in a judgemental or coercive manner. ‘Health care providers should share their knowledge and experience with parents, because that information helps with decision-making while allowing them time and space to weigh the option.’ (Rapoport et.al. 2013) This supports and acknowledges parental autonomy.

There are different reasons for withdrawing or withholding treatments. The decision must be made sometimes, as the treatment is particularly unpleasant and the burden on the child considered being greater than the overall benefit. The treatment may add quantity to life but will not cure the illness. The healthcare team in conjunction with the family may decide to withhold some treatments not considered to be in the child’s best interest, e.g., mechanical ventilation, but may continue other treatments which are in the child’s best interest, e.g. artificial nutrition and hydration. For other children, in different circumstances, any life prolonging treatments may be considered to be disproportionate, or not in the child’s best interest. These decisions may occur when the symptoms of the underlying illness are considered to be overly burdensome or that they are unable or unlikely to benefit from continued life. As Larcher et.al, (2015), stated ‘Any proposed treatment should confer maximum benefit and minimise harm, consistent with its intended purpose.’
This is arguably the most difficult aspect of paediatric palliative care and is acknowledged by the development of the 2015 UK guidelines *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*, the Royal College of Paediatrics and Child Health offer three sets of circumstances when treatment limitation can be considered because it is no longer in the child’s best interests to continue:

- When life is limited in quantity, e.g. brain stem death or when death is imminent or inevitable and the LST is of no overall benefit.
- When life is limited in quality, this is when the treatment may prolong life but will not alleviate the burdens associated with illness or treatment itself.
- Informed competent refusal of treatment.

This document ‘is intended to provide an ethical and legal framework for making decisions to limit life-sustaining treatments (LST) in life-limiting and life-threatening conditions in children.’

Also the European Council in 2014 published a ‘European Guide on the decision-making process regarding medical treatment in end of life situations’, written both for patients and medical personnel, giving advice for shared decision making by patients, physicians and nurses.

**Respect for Children’s Autonomy**

In the words of Barfield et al. (2010) ‘...it is our ethical imperative to search for methods to incorporate children’s preferences into the decision-making process at the end of life.’ Children’s autonomy should be developed and promoted by their parents. Supporting children’s independence and autonomy is the long-term goal of most parents and healthcare providers in order to help the child become an adult with good moral beliefs and values. It is the role of a parent to help mould and guide a child to be able to make autonomous decisions in their future. However, when a child has a LLC, it can be questioned as to whether or not they will ever truly develop into autonomous beings. In light of this situation it can be questioned, whether
the parent’s autonomy trumps that of the child? Should the healthcare professional explicitly support the parents’ decision making?

The benefits of children being involved in all aspects of their care, from the time of diagnosis, through to the decisions being made concerning their end of life care has been highlighted in many arenas. Children's opinions, by law are required to be sought and due weight given in accordance to their age and level of maturity. Parents and healthcare professionals often find it excruciating to endure conversations regarding these grave situations with the child. The absence of these conversations makes it impossible for the child to participate in autonomous decision making. ‘...and the pursuit of a path of care that is in the child’s best interest while respecting the child’s emerging capacity to make reasonable decisions that may be contrary to the decisions of the parents.’ (Feudtner and Nathanson 2014)

In these situations the healthcare professional must advocate to promote the child’s autonomy and to encourage the parents to accept the child’s involvement in their own care. Michelson and Steinhorn, (2007), described the benefits of this by saying, ‘By focusing attention on age- and developmentally-appropriate personal goals children can maximise the quality of their time with family and friends.’

Respect for the Healthcare Professional’s Autonomy

‘Occasionally in medical ethics, an autonomy interest is minimal and a medical benefit maximal, warranting a paternalistic intervention by the physician.’ (Beauchamp, 2003) At times decisions are too difficult or extremely medically based and there may be benefit from a paternalistic approach by the healthcare professional. One of these situations may be in relation to ‘palliative sedation.’ The European Council’s Guide to Decision making (2014) defines sedation for distress in the terminal phase as,

‘Sedation seeks, by means of appropriate medication, to reduce awareness to a degree which may extend to loss of consciousness. Its aim is to alleviate or remove the patient’s perception of an unbearable situation when every available treatment adapted to this situation has been offered and/or
dispensed but has failed to bring the expected relief. The aim of sedation is not, therefore, to shorten life.

‘Palliative care is intended to alleviate the harms produced by illness and disabilities and is consistent with the moral duties of medicine.’ (Larcher et al. 2015) The concept of “double effect” has been well documented in palliative care research. End of life pain and distress must be controlled in order to facilitate a “good death” for the child. Sedation is only ever used when all other available means have failed to adequately control symptoms. ‘Appropriate administration of opiates to a well-monitored, symptomatic patient is unlikely to stop breathing and hasten death.’ (Michelson and Steinhorn, 2007) The consequences of administering medication to achieve levels of comfort may require the healthcare team and the family to make the decision to sedate the child to a level of unconsciousness when the child is near death. A balance must be struck between the protection of life and the child’s right to be relieved from suffering. All potential consequences and reasons for sedation must be explicitly explained to the family. It is the intention of the healthcare professional here that is important. The intent must be to relieve pain and suffering only, not intent to hasten the child’s death. ‘If support is truly titrated to meet the patient’s need, and attempts have been made to use more routine dosing, then, ethically, terminal sedation or palliative sedation can be justified by the concept of “double effect.”’ (Leeuwenburgh-Pronk et al., 2015)

When making decisions in relation to limiting life prolonging treatments, it is important for the healthcare professional to provide adequate, impartial information without unduly affecting familial autonomy. In a study conducted by de Vos et al. (2015) it emerged that, ‘Physicians wanted to guard the child’s life and well-being, but they also wanted to protect the parents from (later) worries and guilt. Yet, this protection was not in line with what the parents asked for, as indicated by their efforts to actively participate in all decision-making stages.’
A delicate balance must be attained between the healthcare professional’s autonomy and the autonomy of the family in relation to paediatric palliative care.

**Beneficence and Nonmaleficence**

While beneficence and nonmaleficence are two distinct principles, when discussing ethics in relation to paediatric palliative care, the principles tend to coexist. ‘The principle of nonmaleficence imposes an obligation not to inflict harm on others.’ (Beauchamp and Childress, pp.149. 2003) The principle of beneficence is not simply the opposite of nonmaleficence. It involves consciously carrying out an action intended to benefit another person. ‘Principle of beneficence refers to a statement of moral obligation to act for the benefit of others.’ (Beauchamp and Childress, pp.197 2003)

‘One of the most difficult ethical dilemmas in paediatrics today arises when a child has complex chronic conditions that are not curable and cause discomfort with no prospect of any improvement on quality of life.’ (Leeuwenburgh-Pronk et.al. 2015) While the advances in medicine has allowed for the survival of children who would have previously died, the question of benefit versus burden is ethically raised.

When, if ever is it ethically permissible to discontinue or not to commence a treatment with potentially life prolonging benefits? This can be particularly challenging when it is the life of a neonate or child who should have potential, and parents are desperately hoping for a miracle. ‘...it is important that prognosis— including the degree of uncertainty about the outcome and the quality of life likely to result—be assessed carefully, on the basis of the best available data, and communicated clearly to parents.’ (Wilkinson, 2016)

The Irish Medical Council, (2016) states,

‘However, there is no obligation on you to start or continue treatment, including resuscitation, or provide nutrition and hydration by medical
intervention, if you judge that the treatment: is unlikely to work; or might cause the patient more harm than benefit; or is likely to cause the patient pain, discomfort or distress that will outweigh the benefits it may bring.’

‘Letting a patient die is acceptable if and only if it satisfies the condition of futility or the condition of a valid refusal of treatment.’ (Beauchamp and Childress, pp.173. 2003) By discontinuing overly burdensome treatments with the agreement of the parents, and the child where relevant, a natural death ensues. Treatments are considered to be overly burdensome if the treatment itself is causing distress to the child and the overall benefit to be gained is minimal. Medical teams must assist parents with this decision making. It is their moral obligation to give the best possible medical advice, both in the best interests of the child and in support of the parents. In a study conducted by Nennhaus and Classen (2016) on end of life decision making in Germany, it found that ‘Concerning the mode of decision making, most participants answered that the clinical team first made up its opinion and then approached the parents.’

The Value of Life

How does one place a value on human life? Who should decide and how, to value the quality of a child’s life? ‘Levels of Well-being are social preferences, or weights that members of society associate with time-specific states of function.’ (Kaplan et.al., 1979) This statement implies that the quality of life is relative to the health of a person at that point in time, it is subjective and changeable.

Quality of life (QoL) in relation to paediatric palliative care and the decision to withdraw or withhold life prolonging treatments is applicable in ‘...situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself.’ (Larcher et.al. 2015) In a study carried out by Huang et.al., (2009) they found that ‘Among children with life-limiting conditions, QoL is the most frequently desired information
that parents would like to receive from physicians as part of shared decision-making.'

**Justice**

Providing a healthcare service involves a series of legal and ethical dilemmas in which there are no right or wrong answers. The healthcare provider in conjunction with many team members and guided by policies and the laws of the State, must weigh up and attempt to find balance and justice in these turbulent situations. In palliative care, as highlighted, most of these relate to decisions about overly burdensome treatments, informed consent and end of life decisions. In addition, there is an increasing number of situations in which the ethical principle of justice emerges; the equal allocation of resources and equal accessibility to healthcare services.

The principle of justice is difficult to sum up. There are various ways of analysing it. One way in which Beauchamp and Childress, (pp.241 2003), describes justice is ‘A holder of a valid claim based in justice has a right, and therefore is due something. An injustice involves a wrongful act or omission that denies people resources or protections to which they have a right.’

Problems of justice are very different in different parts of the world. Resources and expertise vary greatly throughout. ‘The right of equitable access to health care of appropriate quality is enshrined in Article 3 of the Convention on Human Rights and Biomedicine.’ (Council of Europe, 2014)

As this group of children, who have a life limiting condition and their families, are more vulnerable than those who do not, and have specific needs, palliative care should be made available to them. As Larcher et.al., (2015) stated, ‘There is a strong moral duty to provide palliative care to children with life-threatening and life-limiting illnesses, whether delivered by a specialist palliative care team or as part of the overall care delivered by the clinical team already caring for the child.’
In Ireland, children may not have access to specialist paediatric palliative care, as a consequence of their geographical location. As mentioned previously, there are small numbers of children requiring paediatric palliative care; therefore it is not possible to justify specialist teams as being cost effective throughout the country. However it can be argued that children with a life limiting condition have the 'right' to treatment with palliative care principles. The specialist team is based in Dublin with the local adult palliative care teams having telephone access to them for advice and guidance. Palliative care should be offered to these children and their families at the time of diagnosis. They should not have to wait until the terminal phase of their illness. As Liben et.al, (2008) declared, ‘Patients should not have to choose between life-prolonging treatments (such as chemotherapy for cancer) and palliative care.’

The benefits of palliative care have been explicitly reported in the research to the children’s quality of life, and enabling them to have a ‘good death’. Therefore, we as healthcare professionals, armed with this knowledge have a moral duty to promote fair access to palliative care for children with life limiting conditions at an early stage of their illness. To deny them that right could be considered an injustice.

‘In public health systems with limited resources, provision of highly costly treatment may mean that other patients are unable to access treatment.’ (Wilkinson, 2016) By openly communicating with the child and family, some of these inappropriately burdensome treatments may be discontinued. End of life discussions are extremely difficult for parents as it means confronting the limitations of medical treatment and voicing the knowledge that life is finite. Palliative care and end of life discussions are to promote patients autonomy, dignity and improve quality of life. If less aggressive, overly burdensome treatments are omitted at the end of life, it will benefit to the cost of running the Health Service. ‘Decreasing aggressive care at the end of life, by reducing frequent hospital and ICU admissions, can lead to decreased use of
cardiac catheterization, dialysis, ventilators, and pulmonary artery monitors, significantly reducing end-of-life cost.' (Bergman and Laviana, 2016) Another study highlighting this stated, ‘Nevertheless, results of our study suggest that increasing communication between patients and their physicians is associated with better outcomes and with less expensive medical care.’ (Zhang et.al.2009) Mack et.al, (2012) concurred with this finding in a study which they conducted regarding less use of aggressive treatments when EoL discussions had taken place.

Effective communication between the healthcare team and the child and family, as shown can reduce the use of aggressive treatments at end of life, which, as a by-product is favourable to the cost effectiveness of paediatric palliative care. However communication must be clear and honest as some parents may fear that a decision to limit treatment for their child is due to a demand on resources or a lack of resources available. The HSE operates a Treatment Abroad Scheme (TAS) for people entitled to treatment in another EU/EEA member state. The TAS allows a Consultant based in Ireland to refer a patient for treatment in another EU member state or Switzerland, where the treatment in question meets the criteria outlined clearly in the policy. Comprehensible information regarding the decision making process and guidelines should be given to parents. A second medical opinion is often beneficial. ‘The decision-making process should be open, honest and accountable; it should avoid factors that could introduce discriminatory access to healthcare. The ethical criteria for decision making should be clearly explained to all.’ (Larcher et.al. 2015)

**Abortion in Ireland**

‘You have an ethical duty to make every reasonable effort to protect the life and health of pregnant women and their unborn babies.’(IMC 48.1, 2016) Abortion is a hot topic currently in Ireland. The legislation around abortion in Ireland was outlined in the previous chapter. The ethics of this will be discussed as many of these neonates require the intervention of the
paediatric palliative care team. ‘Early communication with the parents and early management of the pregnancy makes sense for the parents faced with the sad and frightening news of foetal abnormality.’ (Tosello et.al. 2014)

One of the difficulties with legalising abortion in Ireland based on the term ‘Fatal Foetal Abnormality’ is that the foetuses given the diagnosis ‘fatal’, or ‘lethal’ may survive for an unprescribed amount of time. ‘There is no agreement on the probability of death that would justify describing a condition as ‘lethal’’. (Wilkinson et.al. 2012)

In Ireland the dilemma is that abortion remains illegal except in the case whereby a mother’s life is considered to be endangered if the pregnancy continues. If a diagnosis of a fatal foetal abnormality is made the couple do not have the choice to opt for a termination in Ireland. They must travel abroad if they wish to pursue this option. ‘Issues of access to termination of pregnancy and gestation limits are matters of professional, political and public debate.’ (Breeze et.al. 2007)

Most antenatal diagnosis cannot be confirmed until after birth. Opting for termination is acting in uncertainty. The long-term outcome of antenatal diagnosis cannot be predicted and some conditions which are considered lethal may not be. ‘Due to constant advances in knowledge, there is no fixed list of LFA’s (lethal foetal abnormalities), and those that enable practitioners to predict rapid death after birth is relatively rare.’ (Tosello et.al. 2014) In a study conducted on the outcomes of “lethal antenatal diagnosis”, it was found that ‘Review of outcomes for malformations commonly designated ‘lethal’ reveals that prolonged survival is possible, even if rare.’ (Wilkinson et.al, 2014)

Regardless of which decision a family opts for, it adds tension and stress to an already enormously fraught situation. ‘They can precipitate ethical, moral, and marital crisis and, in many cases, leave an aching void from the loss of the fetus.’ (Wool, 2011) Perinatal palliative care needs to be discussed at the time of diagnosis and the benefits of it highlighted. Parents need to be given
the information regarding the benefits of having the opportunity of meeting and caring for their baby, even if it is only for a short time. ‘With dedicated resources, guidelines and training, and an agreed framework for practice, more parents could benefit from perinatal palliative care as an alternative to termination of pregnancy.’ (Breeze et.al. 2007) The role of the PPC team is to support the family in whatever decision they make.

It is beyond the scope of this dissertation to provide a detailed discussion of the legal or ethical approach to abortion law in Ireland. ‘However, in countries where the diagnosis of a ‘lethal malformation’ is legally required prior to termination, there may need to be further clarification about which definition of LM (lethal malformation) is to be used.’ (Wilkinson et.al. 2012) This is particularly relevant if the law is to change in Ireland.

**Conclusion**

Whilst the ethical issues in paediatric palliative care have been discussed under the four principles it is important to state that no one principle trumps the other. Rather, the dilemmas are examined under the principles and each given due weight. A balance is required in order to make an ethically sound decision.

‘Past decisions about moral rights and wrongs in cases serve as a form of authority for decisions in new cases. These cases profoundly influence our standards of fairness, negligence, justified paternalism, and the like.’ (Beauchamp, 2003) This highlights the way in which ethical decision making and legal guidance are entwined.

Ethics guides practice for all healthcare professionals. The ethical issues in paediatric palliative care are highly emotive and require moral decision making from the triad of stakeholders, the child, the parents and the healthcare team, all with the intention of maintaining a good quality of life for the child. As discussed, the ethical dilemmas often begin even before birth with an antenatal diagnosis of a life limiting condition and continue to end of life. The intention of all parties is always the same, to promote care that has
the child’s best interest at heart. ‘Our study reveals that parents feel the
same double duty as physicians, making certain that everything is tried to
save their child’s life while protecting their child from suffering, without
sufficient quality of life.’ (De Vos et al. 2015)
Chapter 7: Case Study

CHARLOTTE’S CASE

The high profile case regarding baby Charlotte Wyatt in the UK in 2004 has been selected to demonstrate the ethical and legal issues which may arise when parents and the healthcare team do not agree on treatment options for the child.

Charlotte Wyatt was born at 26 weeks’ gestation weighing about 458 g in October 2003. She had multiple medical problems. All the professionals caring for her acknowledged that she was severely brain damaged and highly unlikely to live for more than a few months whatever was done for her. She did not respond to stimulation but she did experience pain and distress. Her parents did not dissent from this gloomy prognosis. Her doctors did not seek to withdraw existing treatment from the baby. Charlotte was being fed via gastrostomy tube and had been placed on a ventilator three times because of serious heart and lung problems. She was on high levels of oxygen. The dispute revolved around whether if Charlotte stopped breathing again she should be ventilated. Ventilation would have caused her further pain and distress. Charlotte’s parents, who were devout Christians, prayed for a miracle and firmly believed that Charlotte could respond to their love and that their child was not ready to die.

Doctors at St. Mary’s Hospital claimed that she was deaf, blind, that she made no movement on her own and that she could feel no sensations except pain. They convinced the court that it would not be in Charlotte’s best interest to be kept alive if she stopped breathing on her own.

Doctors at St Mary's hospital in Portsmouth, where Charlotte had been cared for since her birth, believed that if she were to stop breathing they should not

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¹ Brazier, M., 2004. Letting Charlotte die. *Journal of medical ethics, 30*(6), pp.519-520. [http://jme.bmj.com/content/30/6/519.2.full](http://jme.bmj.com/content/30/6/519.2.full)
resuscitate her because her quality of life would have been so poor. They said it would have been "futile, or even cruel" to have put the baby on a ventilator if she developed breathing problems.

The order which lies at the heart of this case is that made by Judge Hedley on 8 October 2004.

Charlotte as a child was considered to lack capacity to make decisions about medical treatment to be delivered to herself for her physical health care.

Judge Hedley ruled that:

Having regard to Charlotte’s best interests, and in the event that the paediatric medical consultants responsible for Charlotte’s case, at (the Trust), the Southampton University Hospitals NHS Trust or any NHS Trust treating Charlotte consider that she is suffering an infection which has or may lead to a collapsed lung, it shall be lawful for the doctors treating Charlotte to provide all suitable medical care including antibiotics.

That in the events anticipated above, and having regard to Charlotte’s best interests:

(i) in the event that the responsible paediatric medical consultants reach a decision that Charlotte’s medical condition shall have deteriorated to such an extent that she is unable to maintain oxygen and carbon dioxide exchange, it shall be lawful for responsible paediatric medical consultants to reach a decision that she should not be intubated and / or ventilated.

(ii) Whilst the responsible paediatric medical consultants may reach a decision that it is appropriate to administer Continuous Positive Airways Pressure (CPAP) to help keep Charlotte’s airways open and to ease Charlotte breathing, if she is visibly distressed by CPAP, it shall be lawful for the responsible
paediatric medical consultants to reach a decision that CPAP shall be withdrawn.

(iii) The responsible paediatric medical consultants shall be entitled to reach a decision to use symptomatic relief which may be in the form of opiates in the knowledge that this may depress Charlotte efforts to breathe whilst making her more comfortable.

Charlotte’s parents said they would not challenge the court’s decision at that time.

Another case concerning an infant with a life limiting condition occurred at that time. The judge in this case said she used as guidance the court’s decision allowing the doctors to refuse a ventilator to Charlotte Wyatt if she were to stop breathing.

In November 2004, six weeks after the court ruling, the Wyatt’s decided to appeal the judgement.

On November 20th the Wyatt’s filed a complaint with local authorities which claimed that the doctors were giving their daughter too much diamorphine. They alleged these levels could have brought about an early death. The hospital said the diamorphine was to prevent Charlotte from suffering.

On Monday 30th November 2004, Charlotte was found to have a fractured femur. This had nothing to do with abuse or mishandling: it was due to her intensively brittle bones. Mr. and Mrs. Wyatt refused to permit the Trust to administer diamorphine to Charlotte fearing that it would affect her breathing. The doctors treating Charlotte made an out of hour’s application that day by telephone to the judge, seeking an extension of the October order to permit diamorphine to be administered. That order was granted, although it was told that thereafter, Mr. and Mrs. Wyatt’s
opposition relented and diamorphine was administered with their consent.\textsuperscript{2}

In December 2004, the High Court’s Judge ruled that doctors at the hospital could use more of their own discretion in varying the use of drugs and medical care they gave to Charlotte, who was fourteen months old at that time.

Her parents believed that she was more responsive and enjoyed ‘cuddles.’

February 1\textsuperscript{st} 2005, the parents again appealed the ruling made in October. The High Court Judge upheld the decision but did grant permission for experts to evaluate Charlotte’s condition. The report was to be given in March.

At the end of March medical experts again told the courts that Charlotte had little hope of improving. They said there had been no brain growth. They acknowledged that she occasionally smiled, but said that a respiratory infection would cause her demise. The medical opinion was that the ventilator would only prolong her death and suffering.

April 2005, while acknowledging that Charlotte’s condition had improved the Judge again ruled that it would still be in her best interest to leave her die if she were to stop breathing.

October 2005, Charlotte’s second birthday the High Court Judge revoked the order because her condition had improved to the point where she might be able to survive.

Even without the court order, however, doctors could still decide to withdraw treatment if they believed in doing so would be in Charlotte’s best interests.

\textsuperscript{2} Wyatt & Anor v Portsmouth Hospital NHS & Anor [2005] EWCA Civ 1181 (12 October 2005)

\url{http://www.bailii.org/ew/cases/EWCA/Civ/2005/1181.html}
Unfortunately Charlotte’s parents separated. Her mother had care of her three siblings and social workers felt that she would not be in a position to provide Charlotte with the twenty four hour care she required. Her father had attempted suicide and was not deemed fit to care for Charlotte. Charlotte left the hospital to live with foster parents in December 2006. She only required oxygen for periods throughout the day; she was eating solid food and playing with toys.

**Ethical and Legal Issues Raised**

This case was not about whether treatment should be withdrawn from Charlotte. It examined the ethical and legal implications regarding deterioration in Charlotte’s condition and as to whether or not it would be legally permissible for the medical team not to intervene with further medical treatment in the form of ventilation.

**Capacity**

Charlotte lacked capacity as she was a young child. She was incapable of demonstrating autonomy. Her parents and the courts therefore were obliged to use the ‘best interest, principle. In the UK, the Children Act, 1989, uses the welfare or paramountcy principle and puts the child’s welfare first in such decisions, comparable to the child’s best interest in Ireland.

**Best Interest**

Parents are generally entrusted to make decisions in their child’s best interest. It is not usually questioned. However in this case regarding Charlotte, the medical team felt that the parents had an unrealistic expectation of her medical condition and outcome. The medical team felt that the parents’ decisions regarding the plan of care for Charlotte in the event of deterioration would not be in her best interest. It is on these grounds that a dispute often arises between parents and healthcare teams. Best interests
are based on individual ethical values. Tiballs (2007) described this by saying, ‘This is not surprising as one’s ethical position is derived from diverse social, cultural, religious, moral and familial influences’. The parents in this case were cited as being devout Christians. In their mind, it was in her ‘best interest’ to survive at all costs. They believed she would grow and develop. Charlotte’s future ‘quality of life’ as perceived by the medical team and the Judge may have been a factor in their opinion also. The Judge stated that her life was ‘intolerable’ at the time. The medical team said she experienced a lot of pain.

In this case the judge agreed with the medical team. In October 2004 Judge Hedley stated ‘The unanimous medical advice is that to give such treatment would not be in her best interests.’

In this case the decisions were based on Charlotte’s best interests alone. A child is deeply embedded in the family unit. In a case like this perhaps the best interests of the family should be considered. As Inwald (2008) stated ‘…the test is too individualistic – it recommends only the child’s interests are considered. Other people’s interests are ignored, particularly those of parents and siblings, or are only considered in so far as they impact on the interests of the child.’

**Rights of the Family**

The law recognises the family unit as the ‘natural primary and fundamental unit.’ In most circumstances the family are best placed to make decisions and to consent on behalf of their child. The value of the rights of the family is only questioned when there is an insurmountable difference of opinion.

**Beneficence and Nonmaleficence**

The medical team treating Charlotte believed that further intervention would cause her more harm than benefit. They felt that if they were to ventilate her again it would cause her serious pain and discomfort and her overall outcome would remain grave. This brings up the ethical issue of
beneficence and nonmaleficence. Beneficence is to act in the child’s best interest. In this case this was to prevent her from further pain and suffering, and allow her a peaceful and dignified death. Nonmaleficence is to avoid unnecessary and overly burdensome treatments. Morrison and Kang (2014), describe this complex situation by saying, ‘Such decisions are typically made when cure or survival with a good quality of life is no longer possible, and the goals of care therefore shift to focus on the comfort of the patient...’ In the case of Charlotte, the medical team believed it would be in her best interest to allow her to die peacefully if she were to stop breathing again.

Consent

It is the duty of the medical team to provide the parents with adequate information, presented in a manner in which they can understand in order for them to give informed consent to treatments. ‘Equally important, one must know how to discuss all of these issues with a patient and family while continuing to support them through what is likely one of the most stressful times of their lives.’ (Morrison and Kang 2014) In this case consent was required for the administration of an opioid analgesic and the permission not to intervene aggressively in the event of respiratory deterioration, but instead administer palliative care. A family’s concept of consent for their child will be based on their own values. In this case the family had a strong Christian faith, and believed that Charlotte would defy the odds. It is the role of the palliative care team to support the parents. They will effectively communicate information regarding treatment options and the expected outcomes for the child. ‘The responsibility of a palliative team is to help parents make the correct decision in the best interests of the child.’ (Postovsky and Arush 2004)

Medical Futility

Medical futility is suggestive and not definitive. The outcome cannot be predicted for sure until after the event. The judicial decision was based on the educated medical opinion of the team, who had also consulted with, and verified their medical opinion with a conferring team. Charlotte’s parents argued against the decision being based on futility. They wished
for their daughter to be given every available option to save her life. On conducting research in this area, Wilkinson and Savulescu (2011) found that, ‘...some patients would regard a chance of this magnitude as worth taking if there were a possibility of recovery or long term survival and the alternative were death.’

Quality of Life

The medical team were in the opinion that Charlotte had no valuable quality of life. She had lived her entire life in the hospital and it was not foreseen that she would ever be able to leave. Through the course of Charlotte’s life she began to show signs of awareness. She smiled a little and followed a moving toy with her eyes. The judge acknowledged that her life could no longer be considered intolerable. Quality of life is dependent on that point in time; it may change according to new attainable goals and values.

Learning from the case

From the available information on the case it cannot be seen as to whether or not there was a trusting relationship between the family and the medical team prior to the case being brought before the courts. Communication obviously met an impassable block, with the parent’s one side and the medical team the other. In this case the courts were asked to intervene and sided with the medical team, overriding parental authority. The case first came before the courts when Charlotte was eleven months old. An early referral to the paediatric palliative care team, prior to the breakdown of communication between the parents and medial team may have prevented an escalation to the court. The medical team also described Charlotte experiencing a lot of pain. The paediatric palliative care team would have been an excellent resource in managing her symptoms also.

- It is not clear as to whether an ethics council was available to assist with communication before asking the courts to intervene.
The parents appealed the decision on a few occasions demonstrating their discontent with the decision made. Again, communication here is crucial. The parents understanding of the medical intervention required and the pain it would inflict on their daughter is questionable. The parents also made allegations against the medical team in relation to the care they were providing which may signify a fractious relationship making trust an issue.

The judge advised the hospital to use best efforts to get parents consent prior to changing any treatment.

The fact that Charlotte survived against the odds and showed some signs of neurological improvement possibly added to the parents’ mistrust of the medical team. It compounded their belief that their daughter would defy the odds stacked against her. It also highlights that medical futility is suggestive and not definitive.

Even though the Judge acknowledged that due to slight improvements in her neurological status, her life could no longer be considered intolerable, he did not change his ruling initially, that in the event of deterioration aggressive intervention should not be commenced. He based his decision on the medical basis that she had irreversible damage to her lungs.

Only after significant improvement on the perceived quality of Charlotte’s life was the ruling lifted. Charlotte’s parents resolved to fight to keep their daughter alive, and won their case. For other parents, who did not put up such a fight, will they regret their decision after seeing this high profile case?

**Conclusion**

The author hopes that this case study presented here has highlighted the complexity of some of the issues and basis for which decisions are made regarding palliative and end-of-life care for a child, when there is a dispute between the parents and the medical team. These issues are emphasised
when a child lacks capacity to participate in the decision making process. Charlotte’s quality of life was questioned as was the decision to offer aggressive treatment which could potentially have prolonged her life. It also shows that there are no definitive answers; Charlotte went home, with foster parents in December 2006. Neurologically she had made great progress, but the doctors continue to stand over their medical opinion that her underlying diagnosis is life limiting.

There is no standard answer when cases like Charlotte’s arise. Each case is judged individually but an ethical basis is needed for decision makers. Tiballs (2008) describes three legal criteria for withholding and withdrawing treatment, ‘These are based on the present and future ‘quality of life’, ‘futility’ of present treatment and a comparison of ‘burdens versus benefits’ of present and future treatment and its discontinuance.’ This case demonstrated all of these components.
In Conclusion: Future Plans and Recommendations to Promote the Advancement of Paediatric Palliative Care in Ireland

The developments of paediatric palliative care in Ireland have been brought about by the admirable collaboration of efforts between voluntary and statutory bodies. Ireland has come a long way in establishing an effective service for children with life limiting conditions and their families since the Assessment of the Palliative Needs of Children in Ireland (DOHC and IHF, 2005). Conversely, as with all new and upcoming specialities there has been and continues to be challenges which must be faced.

The HSE National Development Committee on Children's Palliative Care has identified ten priorities to be addressed from 2016 to 2020. A national strategic approach to the provision of in-home and out-of-home respite for children with life-limiting conditions, the appointment of a second Consultant Paediatrician with a Special Interest in Palliative Care, to be based at Temple Street Childrens University Hospital, the appointment of additional Children’s Outreach Nurses for Life-Limiting Conditions, A strategic approach to the development of bereavement services and further development of children’s palliative care education programmes as well as an innovative research and evaluation programme for the sector, are amongst some of these core priorities.

Palliative care is available in every county in Ireland; yet, there is varied access to specialist inpatient units, multidisciplinary involvement and respite care. As a result of the geography of the country and the establishment of services within it, many children continue to lack required services, particularly community based ones. Children with life-limiting conditions tend to have a host of complex needs and their care places a huge burden on families. The need for respite to support families remains an urgent objective for the National Development Committee going forward.

In order to provide respite, competent staff must be available to provide care for the children. Education of medical, nursing and indeed all staff providing care to children with palliative care needs has been highlighted as an
objective for the promotion of paediatric palliative care in Ireland and across the world. ‘Physicians and other health professionals—even those with substantial experience caring for the seriously ill—commonly lack skills in eliciting the goals, preferences, and values of their patients and in effectively tuning their care to align with those aims.’ (Gawande, 2016) Not all children with a life limiting condition will require the expertise of a specialist paediatric palliative care team. Hence, it is important that all healthcare professionals receive education and training on the core principles of palliative care.

In 2011 a taskforce was established by the European Association of Palliative Care (EAPC) to gather information, collect data and perform a gap analysis on palliative care for children and adolescents. The European Report from the Children’s Palliative Care Education Taskforce (EAPC, 2014), and the Irish Core Competencies for Children’s Palliative Care (HSE, 2014) offer a very useful structure to outline the requirements for Continuous Practice Development (CPD) within paediatric palliative care in Ireland. An Ethical Framework for End of Life Care was published in 2011. It consists of eight modules of learning and is aimed at fostering and supporting ethically and legally sound clinical practice in end-of-life treatment and care in Irish hospitals and healthcare settings. Again this was a joint initiative between University College Cork, Royal College of Surgeons in Ireland and the Irish Hospice Foundation. This resource can be downloaded for free. There is also a new course commencing in September, Children’s Palliative care/Complex care in University College Galway. We are making headway in relation to the education of professionals.

Education of the public is also a vital factor in promoting palliative care. Part of Irish culture has been to avoid speaking of death; we can see this by the use of euphemisms such as, ‘passed away’. People must be encouraged to talk about death and dying. The Irish Hospice Foundation has a public awareness initiative ‘Think Ahead’, aimed at encouraging people to discuss their end-of-life care preferences and to have them recorded. In the event of an accident or inability to communicate preferences at the time, this discussion has taken place with someone who will communicate preferences
on their behalf. Whilst this is an adult based initiative, its principles can be applied to the paediatric cohort with life limiting illnesses also.

The timing of referral is an issue which needs to be addressed. Studies have demonstrated the benefit of an early referral for the child and family’s quality of life but also for the effective maintenance of the health service. A palliative care referral can promote the effective use of resources by limiting costly aggressive treatments at the end of life. Whilst this is a topic people may not like discussing it is a hugely important factor for society at large. ‘It is ethically imperative to control medical costs and to use resources justly and effectively, both throughout the health care system and in the domain of end-of-life care.’ (Jennings and Morrissey, 2011)

In order for families to feel supported in caring for their children at home, there is a need for 24 hour access to advice and support as recommended by EAPC (2007). This could be provided in the form of telephone access to a healthcare professional with education and expertise in the field of paediatric palliative care. It may be in the form of a paediatric medical doctor with some training in PPC or a Clinical Nurse Specialist in PPC. Families need the reassurance of having support in the middle of the night if their child is experiencing unpleasant symptoms.

Further research is needed in this specialised field. As the field of paediatric palliative care is so small it is important to collaborate with other countries in relation to research and sharing of knowledge gained. This will help the area globally to improve and coordinate efforts to provide an effective and equitable service. ‘Investment in research and teaching has to be priority for the future to ensure existing foundations are solid, and effective ways of working are embedded in future healthcare systems.’ (Hain et.al. 2012)

**Personal Recommendations**

According to WHO (2012), ‘Worldwide, over 20 million people are estimated to require palliative care at the end of life every year. The majority (69%) are adults over 60 years old and only 6% are children.’ As a result it can be seen
why adult palliative care specialists and general paediatricians are tasked with the care of children with life limiting conditions. As a result of this it is imperative that adequate education is provided to these professions in order to deliver an excellent level of care to these deserving children and their grief stricken families.

Nonpalliative general paediatricians will continue to be the primary carers for this cohort of children. Palliative care principles should be incorporated by all members of the healthcare team and education provided at an undergraduate level.

A Compulsory Paediatric Palliative Care component for all paediatric medical and nursing trainees is required.

In addition, as community adult palliative care teams are usually administering the hands on care and management in the child’s home, it is recommended that a paediatric module for all adult palliative care providers, again for both medical and clinical nurse specialists, be made compulsory within the training programme.

This dissertation has demonstrated the enormous benefits of an early referral to the palliative care team using an integrated approach to care and incorporating a multidisciplinary team approach. The uncertainty of prognosis of these life limited children should serve as instigation to a referral, not a barrier.

Despite considerable progress made thus far, there is an opportunity to become world leaders in the ongoing development of this significant speciality. The momentum needs to be continued to ensure that we do all that is morally required of us by each and every child living with a life limiting condition, in order for us to enable them and their families to live their lives to their full potential.

‘The butterfly counts not months but moments, and has time enough’. 
_Rabindranath Tagore b.1861_
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Appendix 1  Advanced Treatment Discussion

Local hospital Name & Logo

Please complete both sides of this form

MEDICAL SUMMARY

(Summary of main clinical problems)

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CONSULTATION

Does this child have the capacity to make and communicate this decision?  
Yes/No

Was the child involved in this decision?  Yes/No  Age of child

...........

Parents/guardians involved in this decision

Name: .................................................................

Relationship........................................................

Name: .................................................................

Relationship: .....................................................

Other family members involved in the decision

Name: .................................................................

Relationship: .....................................................
The decision to limit advanced care may only be recorded with the full agreement of the primary consultant in charge of this patient’s care.

I confirm that both the diagnosis and prognosis have been appropriately investigated and agreed with the parents/guardians.

I confirm Advance Treatment Plan is now approved

Print Name: ...........................................................................

Bleep No. .........................

Signature: ...........................................................................

Date of Initial Decision: .................
ORDER SUSPENDED

Effective From: …………………..To: ………………..

Reasons for decision: ………………………………………………………………………..

Print Name: ………………………………………………………

Signed: ………………………………………………………………………

Bleep No :…………………………………………(Consultant or nominated deputy)

Copy to: ↑ Patient Record ↑ Parents ↑ E.D ↑ Patients G.P ↑ DOPHN

Sent by
## Appendix 2 ACT Categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>Category 1</td>
<td>Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failures of heart, liver, kidney.</td>
</tr>
<tr>
<td>Category 2</td>
<td>Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.</td>
</tr>
<tr>
<td>Category 3</td>
<td>Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.</td>
</tr>
<tr>
<td>Category 4</td>
<td>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.</td>
</tr>
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Appendix 3 Pyramid of Palliative Care Specialities

Children and young people with palliative care needs and their families can access the services they need according to the different stage of the child’s condition.

**Specialist palliative care services**
- Tertiary specialist paediatric care and symptom control

**Core palliative care services**
These form the majority of services required by children and young people with palliative care needs and their families, e.g. community nursing teams, hospices, bereavement services, sibling support.

**Universal services**
The foundations for a good palliative care service includes services which are available to all children and young people, e.g. GPs, education, playgroups.

A key worker will be responsible for ensuring joined-up and co-ordinated service provision.