

# **End-of-Life Care in Ireland: ethical challenges and solutions**

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Submission to the Joint Committee on Health and Children

Dr. Joan McCarthy 24 October 2013

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## INTRODUCTION

**1.** In 21<sup>st</sup> century Ireland, we are witnessing a fundamental change in the way we die. With this change, has come a readjustment of the expectations of patients and families and a rethinking of the goals of medicine and the roles of health professionals.

**2.** Death in the past before medical advances: came sooner, often as a result of acute infection, childbirth, accident, the progression of an untreated disease. Death in the present amid advanced medical technologies: comes later, postponed and managed in intensive medical settings, and often follows one kind of medical decision or another. With medical technology we gain greater control over how and when we die. With greater control comes greater responsibility for the range of complex decisions medical technology makes available.

**3.** One of the goals of the Irish Health Service Executive Strategic Plan for 2008-13, is 'to develop the role of the "expert patient", especially those with long-term illnesses, in developing their own care plan and in looking after their own condition'.<sup>1</sup> Two of the related actions to achieve this goal are: the promotion of patients as 'partners with health professionals' and the education of staff on the 'importance of patient involvement in their care'.<sup>2</sup> This HSE strategic plan linking as it does, the notion of patient autonomy with the idea of individual participation in care planning and self-care, reflects the changes in the way in which illness is managed in the 21st century by health professionals and, increasingly, by patients themselves. It is directly relevant to one particularly vulnerable group of individuals: patients who are dying. However, while more than 4 out of every 10 people in Ireland die in acute care settings; end-of-life care is not seen as a core activity of hospitals, and it is not normally included in service plans for patients and families. Neither is its importance adequately reflected in hospital culture and organisation.

**4.** Currently Irish legislative and regulatory bodies are driving reform in relation to medical practices in end-of-life care. This is a long time coming and is to be welcomed. However, if the reforms envisaged in documents such as the National Consent Policy (2013) and the Assisted Decision Making Bill (2013) are to come about in the fullest sense; there has to be a cultural shift in healthcare institutions and practices as well as among the general public.

**5.** Similar reforms in the US for example, have been seen to be excessively driven by the law and some argue that there is a need for society more broadly to catch up.

*The next decades should be, we believe, a time of education and soul-searching discussions in communities and at kitchen tables, as well as in health care settings. [...] We must talk about what we dare not name, and look at what we dare not see. We shall never get end of life care 'right' because death is not a puzzle to be solved. Death is an inevitable aspect of the human condition.*

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<sup>1</sup> Health Service Executive (2008), *National strategy for service user involvement in the Irish health service 2008-2013*, Department of Health and Children, Dublin, p.14.

<sup>2</sup> *Ibid*, p.6

*But let us never forget: while death is inevitable, dying badly is not.*<sup>3</sup>

**6.** We might live in an age of instant solutions but ethical problems in end-of-life care are not easy to resolve because they involve value-laden opinions and strong personal emotional responses. The increasing diversity of the Irish population and the need to respect different cultural values and religious perspectives also demand greater sensitivity, deeper understanding and more inclusive policies and practices. Ethics is increasingly everyone's business: we can't just leave ethics to the ethical 'experts'; nor can we assume that clinical expertise implies ethical expertise.

**7.** Given the current national and international focus on the processes of death and dying in healthcare settings, the Hospice Friendly Hospitals Programme (HfH) of the Irish Hospice Foundation has made and continues to make a timely contribution to what has been called a 'national conversation about death in Ireland'.<sup>4</sup> One of its many significant initiatives is the **Ethical Framework for End-of-Life Care**.<sup>5</sup>

## **ETHICAL FRAMEWORK FOR END-OF-LIFE CARE<sup>6</sup>**

**8.** The **Ethical Framework**, consisting of 8 Modules of Learning, is a set of resources for health professionals, allied professionals, healthcare ethics and law lecturers and students, to support and enhance teaching and learning about the diverse ethical issues that arise in relation to death and dying.<sup>7</sup> It aims to foster and support ethically and legally sound clinical practice in end-of-life treatment and care in Irish hospitals and healthcare settings. The outcome of a unique collaboration between University College Cork, the Royal College of Surgeons in Ireland and the Irish Hospice Foundation, it has contributions from ethicists, legal experts, theologians, sociologists and clinicians.

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<sup>3</sup> Murray, TH, Jennings, B., (2005) The quest to reform end of life care: rethinking assumptions and setting new directions, *Hastings Centre Report*, Nov-Dec; S52-7, p.57.

<sup>4</sup> Doyle, E. (2008) A National Conversation about Death, unpublished Thesis, University of Edinburgh, p.25.

<sup>5</sup> See Appendix 3 for authorship of the Framework and empirical research.

<sup>6</sup> The Ethical Framework is available (free) online at:

<http://hospicefoundation.ie/publications/ethics/> It is also published by Cork University Press: *End-of-Life Care: Ethics and Law* (2011)

<sup>7</sup> The 8 Modules of Learning (combine ethics, laws and professional guidelines):

1. Explaining Ethics
2. The Ethics of Breaking Bad News
3. Healthcare Decision-making and the Role of Rights
4. Patient Autonomy in Law and Practice
5. The Ethics of Pain Management
6. The Ethics of Life Prolonging Treatments
7. The Ethics of Confidentiality
8. Ethical Governance in Clinical Care and Research

**9.** The Framework draws on a range of values and principles that have been identified as important considerations in end-of-life decision making by international experts in bioethics and by professional codes of conduct, policy documents and laws. One of its unique features is that is also informed by extensive national research - the first national survey of the general public with a focus on ethical issues that arise at the end of life<sup>8</sup>; and the first description and analysis of the ethical views and experiences of Irish health professionals.<sup>9</sup>

**10.** While this research indicates that the general public, patients, families and health professionals have many positive experiences in relation to end-of life care in Irish health care settings; the research also paints a picture of

- a. a general public that have little or no understanding of end-of-life treatment and care terminology and
- b. are not very comfortable with or informed about the processes of dying and death
- c. are confused about the role of families in relation to receiving information and making decisions for incompetent patients and many assume (incorrectly) that families have a right to make decisions about the medical treatment of their loved ones.
- d. This confusion can create difficulties for health professionals especially in situations of family conflict.
- e. On the one hand, there is general agreement that competent individuals have the right to refuse medical treatments even if this decision results in their death and
- f. most people also place emphasis on the quality of their life rather than on its length, and they fear being helpless and dependent more than they fear death.
- g. On the other hand, health professionals indicated that active medical interventions and treatments were continued long after some practitioners thought them beneficial.
- h. There was little or no documentation of patients' wishes in acute or community hospitals.
- i. Many deaths are managed in a moment-by-moment decision-making process embedded in uneasy communication between distressed relatives and under-resourced and over-stretched healthcare staff.

(See **Appendix 1** for a more detailed description of these points)

## **TO ENSURE THAT PEOPLE DIE WELL IN IRELAND**

**11.** What is certain is that if the notion of the 'expert patient' who is empowered to participate in decisions about their treatment and care, as envisaged in the HSE Strategic Plan, mentioned at the outset, is to be realized; **educational and**

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<sup>8</sup> See Weafer (2009), Weafer et al (2009) and McCarthy et al (2010). Given that the sample surveyed in Weafer et al (2009) (n = 667) was representative of the general population and that the study's findings are consistent with related research undertaken in Ireland, confidence can be placed in the representativeness of the survey results.

<sup>9</sup> See Quinlan and O'Neill (2009) for more information about their research involving 14 focus groups; 57 interviews; 102 written submissions with different health care staff in 15 hospitals (both acute and community) around Ireland.

**support strategies** need to be put in place to start and/or continue conversation and debate about the processes of death and dying in Irish healthcare settings e.g.

- a. the lack of familiarity with terms used in relation to end-of-life treatment and care places an onus on state agencies and healthcare organisations to ensure that basic information about end-of-life care is communicated in a meaningful way to the general public.
- b. there is an onus on professionals and hospitals to ensure that patients and their families are aware of the processes of decision making for competent and incompetent patients and the role that individuals and families might have in any deliberations and care plans.
- c. while legal challenges in relation to assisted suicide and euthanasia might capture the public imagination, clarity and understanding are also needed in relation to more routine but also complex and contested decisions and interventions such as starting, stopping and descalating treatment, sedation and pain management and the provision of nutrition and hydration.
- d. Patients do not always want what is right or reasonable to want. It is important to recognize the ethical work of health professionals and to acknowledge that it may come at a personal cost. There is a need for ethical leadership, moral teamwork and for ethically healthy organisations that encourage open, inclusive and respectful dialogue about ethical, professional and legal issues. In this way, nagging doubts and uncertainties can be expressed and shared, the personal cost of acting ethically is not unbearable and sight is not lost of the fundamental bond between professional and patient

**12.** In turn, further **research** into the relationships between patients, families and professionals and the ethical climate of healthcare organisations is needed e.g.

- a. The Irish population is racially, ethnically and culturally diverse. Considering that 3.9 of 4.2 million people supplied a religion in the 2006 Irish population census and that 87% of respondents in our research stated that spiritual and religious support at the end-of-life were important to them, the impact of religious belief on death-related attitudes in Ireland presents an important area for further research.
- b. There is need for research in relation to the disclosure needs and concerns of particular patient groups and their families such as individuals with intellectual disability or mental health problems who have also been diagnosed with serious or terminal illnesses.

## **SUGGESTED SOLUTIONS**

### **A National Network of Clinical Ethics Committees**

**13.** Providing formal ethics support for health professionals and allied staff in the everyday treatment and care of patients and their families by introducing Clinical Ethics Committees into Model 1-4 hospitals in Ireland would bring Ireland into line with international best practice. In Canada, Europe, the UK, US and Australia such multidisciplinary committees perform a threefold function:

- a. Ethics education for health professionals, hospital staff, patients and families
- b. Formulation and review of hospital policies
- c. Consultation to support staff with complex and difficult clinical cases.<sup>10</sup>

**14.** While every hospital would have its own Clinical Ethics Committee [at least 10 hospitals in Ireland already have some form of a Clinical Ethics Committee e.g. Beaumont and The Bons Secours]; each Committee would also be linked at local, regional and national levels with other Clinical Ethics Committees. The work of the Committees would also be supported by key experts in ethics, law and related disciplines working in third level institutes and universities. In turn the Committees would be linked with the educational and research programmes of the National End-of-Life Healthcare Ethics Observatory described below. It is envisaged that the economic cost of each hospital Committee would be minimal (largely administrative) while a small task force in the Department of Health and Children would be responsible for coordinating and supporting the Network at a regional and national level.

### **A National End-of-Life Healthcare Ethics Observatory**

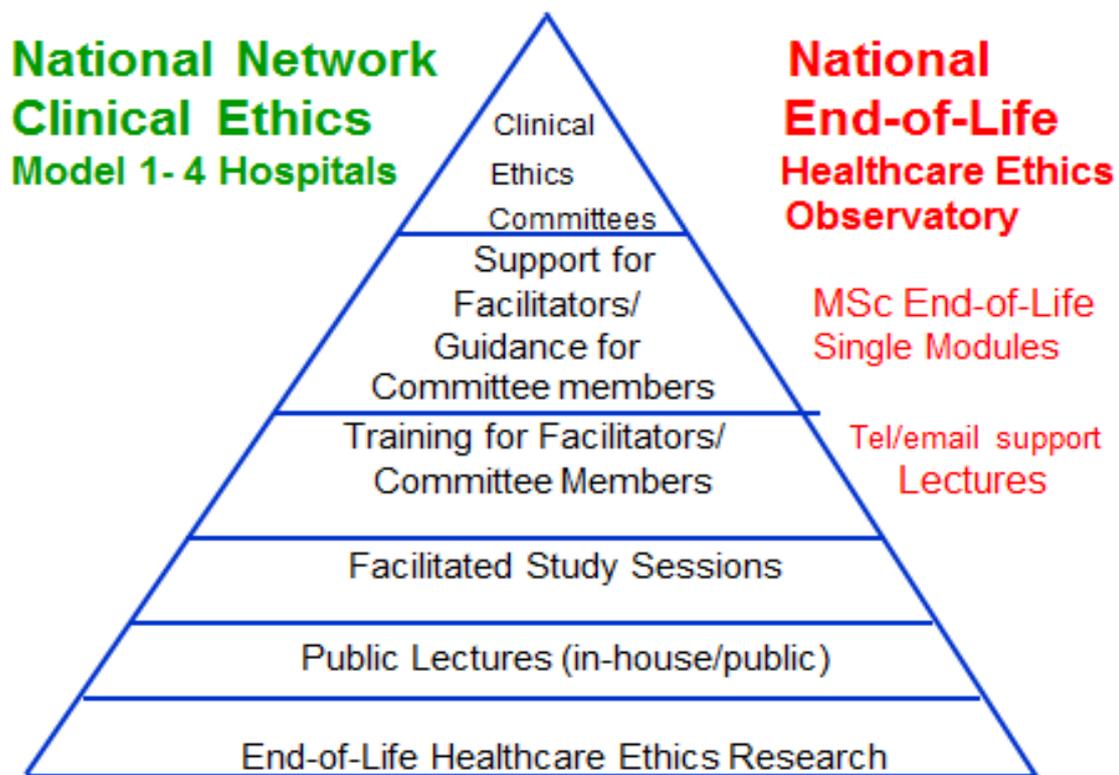
**15.** The Observatory would be the joint initiative of third level educators in ethics, law and related disciplines drawn from relevant institutes and universities in partnership with hospital education centres and professional bodies in Ireland. Given current economic constraints the Observatory might begin as a Virtual Observatory (supported by a network of suitably qualified individuals and housed in one or more third level institution) with a view to finding accommodation in the longer term in a large national or regional hospital. Building on the collaboration between UCC and RCSI that resulted in the development of the Ethical Framework, the work of the Observatory would include:

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<sup>10</sup> See Module 8, Ethical Framework for End-of-Life Care, for further explanation and analysis of Clinical Ethics Committees

- a. Providing educational support to the general public in the form of lectures, workshops and dissemination of information through the social media.
- b. Improving the training and continuous professional development of clinicians involved in caring for dying patients e.g. stand-alone modules, certificate and postgraduate programmes on end-of-life healthcare ethics.
- c. Developing and updating the Ethical Framework and accompanying Study Sessions to ensure they are current, relevant and fit for purpose.
- d. Initiating 4<sup>th</sup> level educational programmes (PhDs and clinical doctorates jointly supervised by academic and clinical experts) in clinical ethics and bioethics in Ireland for clinicians, ethicists, lawyers, chaplains etc.
- e. Supporting the work of Clinical Ethics Committees with expert advice and educational interventions.
- f. Undertaking evidence based ethics research e.g. to evaluate the effectiveness of interventions such as educational initiatives in improving ethical practice or the development of interventions to enable vulnerable populations to participate more fully in end-of-life decision-making.

**16. The National Network of Clinical Ethics Committees and the National End-of-Life Healthcare Ethics Observatory** would work together in educational and research initiatives that would contribute to improving the culture and organisation of death and dying in Ireland. Ultimately, they would positively impact on the care of all patients, service users, family members and staff working in healthcare. A visual representation of how the work of the two initiatives would overlap is provided below.



**17.** A number of the educational initiatives referred to above have already been developed e.g. an MSc in End-of-Life Healthcare Ethics was offered by UCC in 2011-2013.<sup>11</sup> Study Sessions that engage health professionals in the Modules of the Ethical Framework have been piloted with health professionals in Limerick.<sup>12</sup> Both of these initiatives have been very positively evaluated. The Framework itself has been very positively evaluated by the Irish national media and by international academic journals (See **Appendix 2**).

**18.** Moreover, where ethics support is a standard part of healthcare organisations, the evidence indicates that health professionals and hospital staff are:

- more self-aware of their own beliefs and values
- more sensitive to moral values at risk
- less paralysed by moral issues
- engage in more dialogue, less debate about the 'right' answer
- postpone judgement
- listen and feel heard
- more willing to engage in a process that will involve some degree of negotiation
- bring reasons for decisions out into the open – greater transparency

Leading to:

improved patient and family outcomes and less moral stress, desensitization and burnout.<sup>13</sup>

**19.** The success of these initiatives to date indicates what can be done with limited resources where individuals and groups commit themselves to making change happen. Clearly, given the evident success of the work of the Hospice Friendly Hospitals Programme, much more can be done with minimal cost but also the support of state agencies working together with regulatory bodies and third level institutions to enhance the quality of death and dying in Ireland.

**20.** This is also an opportunity for Ireland to take a leadership role internationally, in the development of educational and clinical strategies that foster and support ethically and legally sound clinical practices in end-of-life treatment and care in healthcare settings.

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<sup>11</sup> The Schools of Nursing and Midwifery, Medicine and Philosophy, UCC offered an MSc in End-of-Life Healthcare Ethics with exit routes for a Postgraduate Certificate/Diploma for health and allied professionals and the general public (2009-11). The RCSI offers an MSc in Healthcare Ethics and Law and some modules have a focus on end-of-life healthcare ethics.

<sup>12</sup> See C. McArthur, 'Pilot Study Evaluating the Effect of the Ethical Framework for End-of-Life Care Study Sessions, MSc End-of-Life Healthcare Ethics, UCC, 2013.

<sup>13</sup> Molewijk B, Zadelhoff E, Lendemeijer B, Widdershoven G. (2008) Implementing moral case deliberation in Dutch health care: improving moral competency of professionals and quality of care. *Bioethica Forum*, 1 (1) 57-65.

## Conclusion

**21.** When the Liverpool Care Pathway was found to have contributed to poor care for dying patients and their families in the UK earlier this year, the reviewers called on the British government to ensure that 'guidance on care for the dying is properly understood and acted upon, and tick-box exercises are confined to the waste paper basket for ever'.<sup>14</sup>

**22.** It has now become abundantly clear that care for the dying is a complex art that demands greater public understanding and involvement as well as greater organisational and professional sensitivity to individual patients and their families. Providing the tools for thinking about difficult ethical and legal issues that arise in relation to death and dying and fostering a range of ethical skills and competencies to ensure that decisions are arrived at in the most reasonable, sensitive and collaborative way possible must be part of any national strategy that is seriously interested in achieving any real progress in this area.

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<sup>14</sup> Independent Review of the Liverpool Care Pathway (2013) More Care, Less Pathway, A Review of the Liverpool Care Pathway. Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212450/Liverpool\\_Care\\_Pathway.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf); page 11.

## APPENDIX 1

### EMPIRICAL RESEARCH ON ETHICAL ISSUES (2008-10)<sup>15</sup>

#### Experience and understanding of death

The Irish general public have little or no understanding of end-of-life treatment and care terminology. They are likelier to know more about euthanasia, assisted suicide and post mortems than they are to know about advance directives, palliative sedation, artificial hydration and CPR. Most people had never heard of the term 'Advance Directive', with more than eight in ten (84%) respondents to the Weafer et al (2009) survey stating they had either 'never heard' or 'heard of but know nothing' of the term.

Many people tend to link the withholding and withdrawing of artificial nutrition and hydration (ANH) as well as certain pain relief measures with the hastening of death and euthanasia. The majority of research participants were confused regarding the implications and procedures associated with a 'Do Not Resuscitate (DNR)' orders. This is consistent with earlier Irish research in this area.<sup>16</sup>

See Figure 1. Awareness of Terminology below.

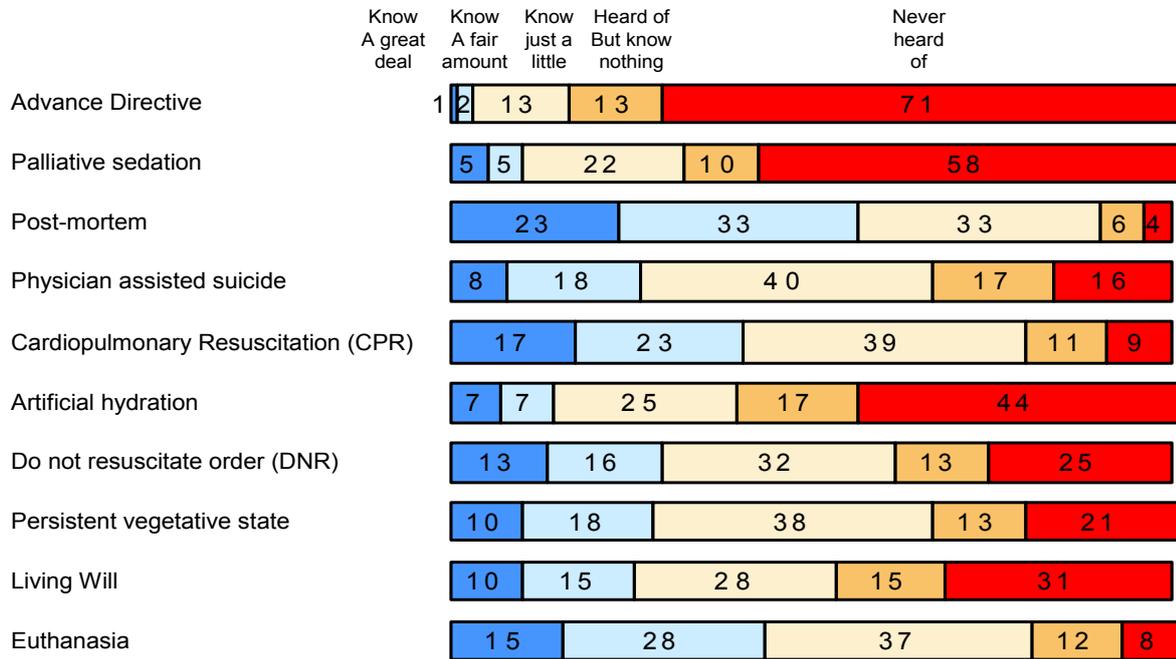
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<sup>15</sup> See Appendix 3 and Reference List for authorship of the empirical research.

<sup>16</sup> Weafer, Research Associates and TNS/MRBI (2004) *A nationwide survey of public attitudes and experiences regarding death and dying*, The Irish Hospice Foundation/Health Services National Partnership Forum, Dublin.

# Awareness of Terminology

(Base: All Respondents, N = 667)



Q. I am now going to read out a list of terms and would like you to tell me if you know a great deal, a fair amount, just a little, heard of but know nothing about or never heard of each term I read out.

Figure 1.

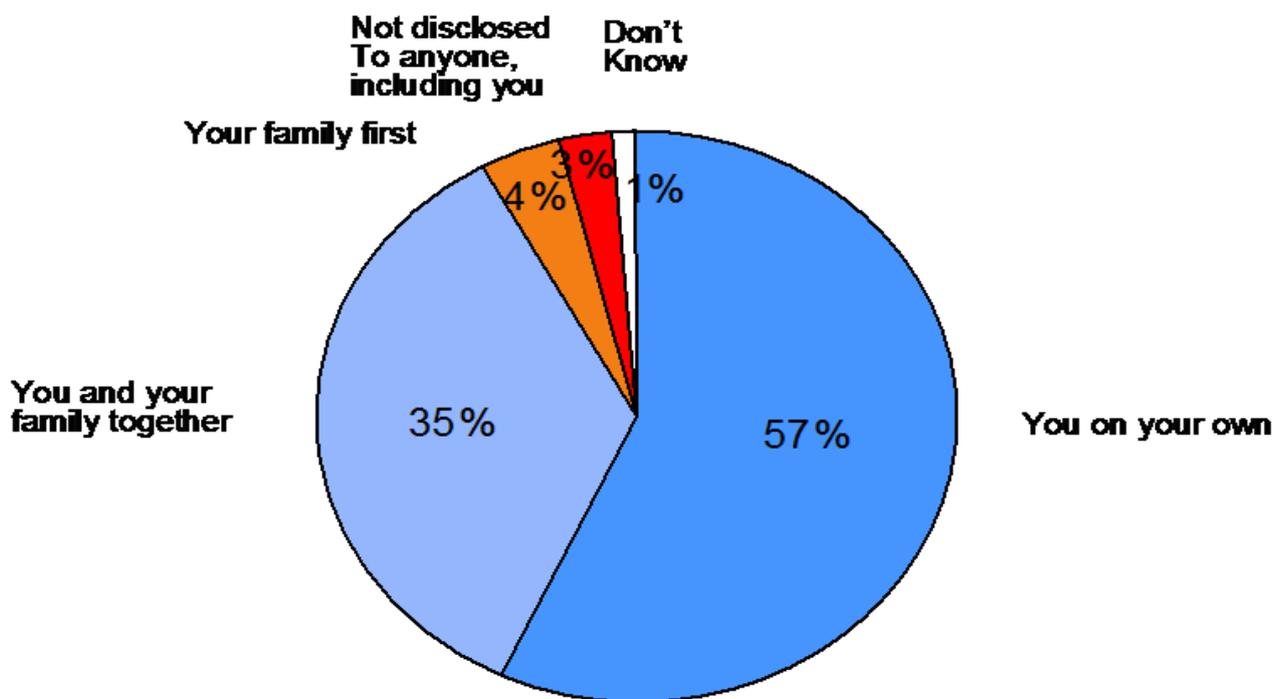
### Breaking Bad News

The findings of Weafer et al. (2009) confirm that most people, if seriously ill, would want to be told the truth about the diagnosis and the prognosis, either alone or in the presence of their families.

See Figure 2. Information of Terminal Illness

## Information of Terminal Illness

(Base: All Respondents, N = 667)



Q. If you were diagnosed with a terminal illness, would you like information about your condition to be told to....?

That said, there remains a strong culture among relatives in Ireland of seeking to protect loved ones from bad news. Some adopt a 'gatekeeper' stance; filtering what they deem the patient should and should not be told. The Quinlan and O'Neill (2009) study found a culture wherein clinicians often liaised with a patient's family either

exclusively or prior to liaising with the patient. Their research with healthcare staff indicated that talking about death is difficult – even for those who work in healthcare and healthcare workers generally feel more at ease having end-of-life discussions with a patient’s family rather than the patient. Where staff are anxious to talk with patients they may be hindered by family members who are uncomfortable with open communication around death and dying.

### **Decision-making**

Many Irish people, particularly older people, place a great deal of trust in their physician when decisions must be made about their care. In our research, most participants agreed that competent persons had the right to refuse medical treatment, but a sizable number also seemed unclear as to who has the authority to make decisions for incompetent patients.

The Irish general public as well as health professionals are confused about the role of families in making decisions for incompetent patients and many assume (incorrectly) that families have a right to make decisions about the medical treatment of their loved ones. This confusion can create difficulties for health professionals especially in situations of family conflict. While the Assisted Decision Making Bill (2013) and the National Consent Policy (2013) clarify who has the authority to make decisions and how those decisions might be made, the findings of our research underline the need to inform and educate the general public and health professionals about the process of decision making in relation to incompetent patients.

Findings of research with health professionals indicated that

- active medical interventions and treatments were continued long after some practitioners thought them appropriate and beneficial
- there was little or no documentation of patients’ wishes

Lack of planning meant:

- many deaths are managed through a moment-by-moment, event by event decision-making process
- embedded in uneasy communication between distressed and grieving relatives and under-resourced and over-stretched healthcare staff.  
(Quinlan and O’Neill 2009 p.4)

### **Attitudes towards death and dying**

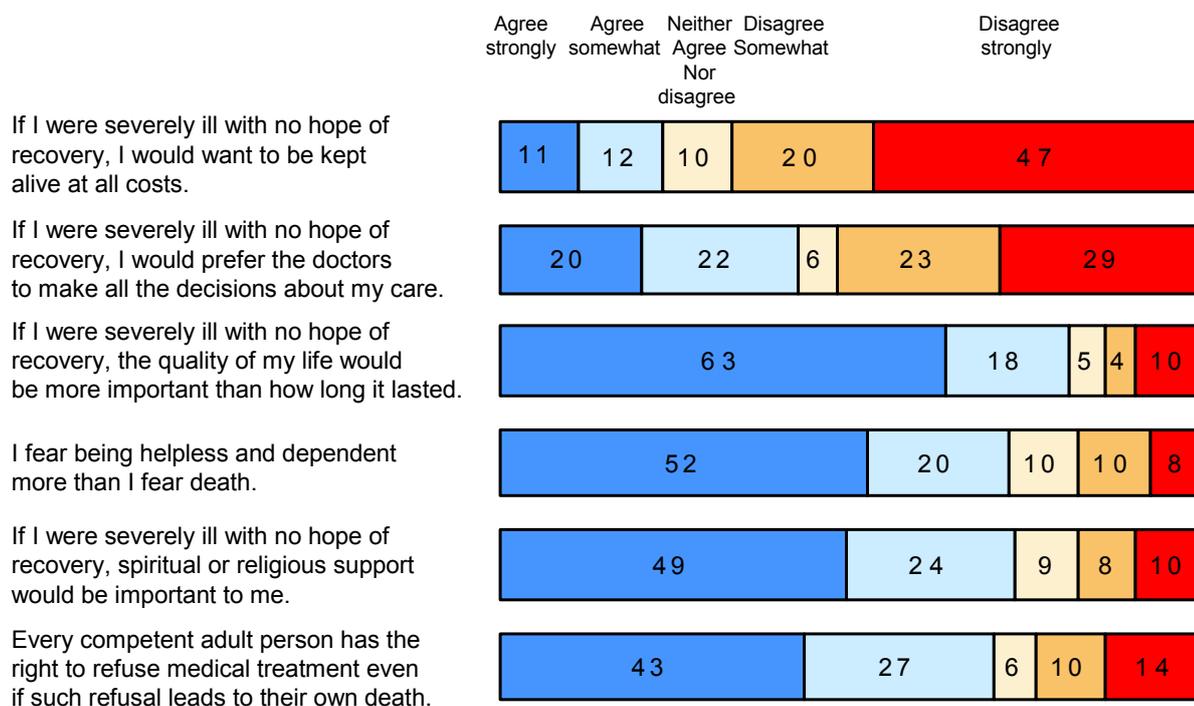
There is general agreement that competent individuals have the right to refuse medical treatments even if this decision results in their death. Most people also place emphasis on the quality of their life rather than on its length, and they fear being helpless and dependent more than they fear death.

See Figure 3. Attitudes Towards Death and Dying

Figure 3

## Attitudes Towards Death And Dying

(Base: All Respondents, N = 682)



Q. I am now going to read out a list of statements and I would like you to tell me whether you agree strongly, agree somewhat, neither agree nor disagree, disagree somewhat or disagree strongly with each statement that I read out.

### Spiritual/religious support

Spiritual and religious support at the end of life are considered very important by the majority of the general public (87%). Those who are religiously committed place a high value on life, reject the right to refuse treatments that might forestall death, respect medical authority and value spiritual support in their end-of-life care.

## APPENDIX 2

### Reviews of the Ethical Framework

*Irish Times* Editorial, 7 October 2010

**Extract:** How often does technology's availability lead to futile treatment, sometimes at immense discomfort to the patient? When is it appropriate to tell someone they are dying? How is a patient's autonomy respected? Is it ethical to withhold nutrition and hydration? ... The framework performs a valuable public service in highlighting issues such as managing pain, confidentiality, governance in clinical care, breaking bad news, healthcare decision-making and life-prolonging treatments. In that regard, it should encourage open public debate and enable healthcare professionals to be collaborative, informed and confident in addressing these matters, however complex and contentious.

Mullock A (2012) *Medical Law Review*, 20(4): 655-7.

**Extract:** As an Irish endeavor, the framework aims to support ethically and legally sound clinical practice in this sector of medical care in Ireland (p.9). As the framework features bioethical principles and ideals which are internationally recognized, together with universally relevant clinical dilemmas, the book has much to commend it to those outside of Ireland.

Tschudin V. (2012) *Nursing Ethics*, 19(3): 443

**Extract:** The book is set within the practice and legal boundaries of Ireland, but its impact is surely way beyond the confines of this one country. The examples and cases used are drawn from practice and have relevance in almost any setting.

Danaher J, *European Journal of Health, Law* 20 (2013) 235-237

**Extract:**

The book has a number of strengths. First, its narrow focus on end-of-life care, and its specific target audience of healthcare professionals, make it a relatively unique contribution to the pedagogical literature in this area. Those of us who teach medical students and professionals dealing with the end-of-life will be hardpressed to find a book that is more appropriately pitched to them ... Designed to encourage critical reflection on key ethical concepts and arguments, these case studies are drawn from real-life clinical reports and legal cases, and are consistently interesting and well-chosen.

## APPENDIX 3

### Biography of Presenter

Dr. Joan McCarthy, MA, PhD is a College Lecturer in Healthcare Ethics in the School of Nursing and Midwifery, UCC. She coordinates the MSc in End-of-Life Healthcare Ethics in the College of Medicine and Health, UCC and also contributes to the MSc in Healthcare Ethics in the Royal College of Surgeons in Ireland and the Medical University of Bahrain. She is a member of the Irish National Advisory Committee on Bioethics, the Ethics Committee of the Nursing and Midwifery Board of Ireland, the Editorial Board of *Nursing Ethics* and the International Centre of Nursing Ethics, Surrey UK. She has published widely on various topics in healthcare and nursing ethics. Her recent publications include *End-of-Life Care: Ethics and Law* (with M. Donnelly, D. Dooley, L. Campbell and D. Smith, 2012, Cork University Press) and *Nursing Ethics, Irish Cases and Concerns* (2<sup>nd</sup> edition with D. Dooley 2012, Gill and Macmillan). She has been involved in a number of national and international research projects and she was the principal investigator of a national multi-disciplinary project that led to the development of the Ethical Framework for End-of-Life Care.

### Ethical Framework for End-of-Life Care

#### Authors:

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**Project Management:** Dr. Joan McCarthy (UCC-RCSI) & Mr. Mervyn Taylor, Hospice Friendly Hospitals Programme.

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**Submission to the Oireachtas Joint Committee on Health and Children  
Public Hearing on end of life care**

**Dr Honor Nicholl,  
Ms. Thelma Begley,  
Ms. Carmel Doyle,  
Ms. Eleanor Hollywood  
& Ms. Carole King,  
School of Nursing & Midwifery  
University of Dublin  
Trinity College.**

**19 November 2013**

## **Introduction**

The authors of this submission are all Assistant Professors in Nursing and Registered Children's Nurses who have experience caring for children\* with life limited illness and those requiring Palliative Care (PC) and their families. All authors have significant specialist expertise in children's nursing and teaching experience in the development and delivery of undergraduate and postgraduate nursing programmes.

Dr. Honor Nicholl PHD, MEd, BSc, RCN, RGN, RNT.

Dr Honor Nicholl is Assistant Professor in TCD. She has a history of teaching, peer reviewed publication and national and international research activity related to children with PC needs. Research includes IHF, AIIHPC, HRB and R&D funded projects including research on differing aspects of the family experiences of PC, transition in PC, family choices in service provision and access and decision-making in PC services. She has received international awards for her work in education and research. In addition Dr Nicholl is involved in clinical service delivery to children at home and has a depth of experience in the development and delivery of educational and clinical programmes in all aspects of children's PC.

Ms. Thelma Begley MSc ,BNS(Hons), RCN, RGN, RNT

Ms Thelma Begley nursing experience is in medical/ surgical nursing and the provision of PC in acute hospitals. She has a particular interest in adolescence and transition from child to adult health services. In view of this the needs of adolescents requiring PC and those with life limited illness who need to transition from child to adult health services are of particular interest to her.

Ms. Carmel Doyle MSc (Nursing), PgDip CHSE, BNS (Hons), RNT, RCN, RNID

Ms Carmel Doyle's clinical and educational background is in intellectual disabilities and children's nursing. As an Assistant Professor she lectures across a variety of both undergraduate and post graduate courses. Her research expertise and activities lie in intellectual disabilities, children with complex needs and associated disabilities, children's PC and interdisciplinary education. She has published in peer reviewed journals on these topics and presented widely nationally and internationally. She has obtained external funding from agencies, more recently for the development of standalone modules in children's PC. She is currently undertaking a PhD in the area of children with serious and complex health needs and intellectual disabilities.

Ms. Carole King MSc, RCN, RGN, RCT, RNT.

Ms. Carole King has an interest in PC and its impact on both the child and their family. She has a particular interest into the nurse's role and interventions which enhance the quality of life during this difficult phase for the child, siblings and family. Carole lectures on communication with children to both undergraduate and post graduate nursing students.

Ms. Eleanor Hollywood MSc, MA, BSc, HDip in Children's Nursing, RGN, RCN, RNT.

Ms. Eleanor Hollywood is Head of Children's Nursing Discipline in the School of Nursing and Midwifery, Trinity College Dublin. Her clinical experience encompasses medical/surgical nursing and nursing care of the neonate. Eleanor is interested in PC for infants, children and young people and how life limiting conditions affect the child and their family.

**\*The term children encompasses birth to adolescence (age 18)**

## Recommendations

There is a need to:-

- develop a comprehensive data set of all children who will require end of life care to enable service provision to be planned.
- develop a community focussed and funded clinical, research, administrative and management infrastructure for children who have end of life care needs.
- develop a coherent and planned national approach to care services for children at end of life that encompasses the contribution of the voluntary and statutory sector.
- increase the number of children's nurses required to deliver care to children who need end of life care in all settings including primary and tertiary care services including in home /out of home respite services.
- develop appropriately skilled interprofessional services/teams for the delivery of primary care services for children who require end of life care in the home/other settings.
- develop a specific specialist career pathway in children's nursing and PC to underpin the increasing requirements for children for end of life care and their families over prolonged periods.
- further develop an interprofessional nationally focussed, competency based educational infrastructure to ensure the competent and effective delivery the end of life care to children and their families in all settings.
- include a national development of transition services for young people with PC needs who will transition to adult services for end of life care.
- fund research activity to underpin best practice in end of life care for children and their families.

## INTRODUCTION

Palliative Care (PC) can be described as a philosophy and a professional practice. It involves an active approach to care from the point of diagnosis or recognition throughout the child's life, death and beyond (Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) & Royal College of Paediatrics and Child Health (RCPCH) 2003).

Children's Palliative Care (CPC) has been defined as a multidisciplinary care strategy designed to relieve physical, social, emotional and spiritual suffering in children and their families by managing symptoms and monitoring all aspects of suffering during the course of the child's illness (Korones 2007). The care should be offered and integrated with other curative or life prolonging care (Korones 2007) and can be provided in the home, hospital or other facilities equipped to support the family. CPC encompasses an interprofessional team of doctors, nurses, chaplain, social worker, psychologist, teacher, special needs assistant, play therapist and care should be provided along evidenced based care pathways.

It is well recognised that the delivery of care to children and their families who require PC services differs significantly from other population groups (WHO 1998, DoHC 2001). The reasons for this include the numbers of children involved, the rarity of the conditions and their specific nature in children. The illness trajectory also differs to that of adults, in that children may not proceed through a continuum of diagnosis to the end of life phase as adults may do, so it encompasses PC during life, during end of life and bereavement care. The need for CPC may extend over many years. Children bring the added dimensions of the developmental, ethical and physiological aspects of PC coupled with the involvement of parents as care givers and decision makers, thereby increasing the complexity of care. Given the nature of some diseases it is also important to note that CPC may encompass numerous members in one family and can also include children with 'no diagnosis'.

With several key documents published in recent years (DoHC/ IHF 2005, DoHC 2010) PC for children has seen some developments. While some recommendations from the National Policy (DoHC 2010) have been achieved such as establishment of a national development committee to oversee implementation of the policy, appointment of national outreach nurses and appointment of a paediatrician in children's palliative medicine, significant gaps remain.

To provide end of life care to children in Ireland on a sustained basis into the future requires that the following issues should be considered:

## **A. ROLE DEVELOPMENT AND EXPANSION**

Nurses contribute to PC for children in a number of roles and settings- practice nurse, school nurse, public health nurse, nurses in acute children's units, children's hospice, learning disability nurses, respite care, adult PC teams, nurses from voluntary sector and CPC outreach nurses. The specific role of the nurse in the provision of care is identified as encompassing the role of planning, implementing and the evaluation of care and also incorporates the roles of a compassionate and knowledgeable care giver, informant, advocate, educator amongst many other roles.

The National Advisory Committee (2001) recommended that all staff caring for children requiring PC should be suitably educated and experienced in caring for children. It has also been recognised that those skilled in PC of adults may lack expertise to deal with the unique needs of children (DoHC/ IHF 2005). Children's nurses are best placed to deal with the medical, social, emotional and psychological needs that young people and their families have. There is a need to expand on the number of children's nurses essential to deliver care to children who require end of life care in all settings and the development of a specific career pathway in children's nursing for this role. Further development of national palliative outreach teams to include more children's nurses and an associated interprofessional pathway is required.

The development of a coherent interdisciplinary CPC team and progression of service will be enhanced with the development of the new Children's hospital that will encompass the expertise currently available within the children's health sector. There is additionally a need to develop services for the delivery of primary care services for children who have PC needs as many children and their families would prefer the site for the provision of end of life care to be at home. This could include a hub and spoke model of care between tertiary and primary care. This requires an adequately funded well educated and skilled workforce. It also requires service planning, planned funded resources to underpin the delivery of complex care at home.

## **B. INFRASTRUCTURE**

As recommended by the National Policy, there is a need to develop a countrywide coherent data set of all children who will require end of life care to enable service provision to be planned. A lack of regional and national data has meant that service provision to date has been inconsistent with shortfalls often being managed by voluntary services. It is therefore difficult to determine where there are gaps in service provision and what is required to address this. This includes the development of a transition service for young people with PC needs who will transition to adult services.

ACT (2001) estimated that between 6,000 and 10,000 young people aged 13-24 in the United Kingdom were living with a life-limiting or life-threatening condition (ACT, Palliative Care for Young People aged 13-24, 2001). This is recognised as a significant underestimation of

the reality. Ireland does not have a corresponding data set. However, there is evidence of the unmet needs of an increasing number of young people living with a life-limiting condition and as they grow will require a move away from family orientated care to young person centred care (ACT 2009). Young people should be empowered to take part in the planning of their care and central to this is a smooth transition from child to adult healthcare services. Transition should include collaborative working and the development of crossover skills between child and adult PC teams in order for there to be a smooth transition between child and adult healthcare (ACT 2009). To ensure this there needs to be good coordination of care between child and adult services. The needs and wishes of young people should be central to the planning process, whilst also acknowledging the support and emotional needs of families. The current ad hoc provision of children's PC services between statutory and voluntary services means that this coordination of care when transition is required is further hampered.

The model of care for children with life limiting and PC requires careful consideration in order that children can receive equal and adequate care regardless of location. There is a need to develop a coherent and planned approach to care services for children at end of life that encompasses and recognises the contribution of the voluntary and statutory sector. Improved home care supports for children and their families at end of life are required to include both funded statutory and voluntary services. The provision of services by voluntary bodies in the last two decades needs to be recognised and the models of care utilised by them can be explored when deciding on a national approach to children's PC. The inclusion of the voluntary sector in local and national PC planning needs to be sustained. Workforce planning is needed to ensure equity of services nationally for all families experiencing end of life care for their child/children.

There is a need to develop funded in home respite services. To date families have had to carry the burden of care for the majority of children with life limiting illnesses in Ireland (Clark and Quinn 2007) and this has a significant impact on parents, siblings and relationships within families. Services such as the one Jack and Jill Children's Foundation provides for home respite services for under 4's need to be expanded particularly for older children and adolescents as there may not be suitable out of home respite services available.

Modern approaches to children's PC require consideration of multiple factors including recognition that children with life limiting conditions are living longer and requiring varying forms of PC (Together for Short Lives 2012; Help the Hospices 2013). Children's hospice care encompasses care for the child within a hospice setting and alternatively within the home. This model is one that is adopted widely in the United Kingdom and is well supported by national policies. In addition the need for a large interprofessional team is evidenced.

### **C. EDUCATION**

In order to develop expertise and a skill base, children's PC should be included in all undergraduate nursing and related health sciences curricula in line with international policy recommendations (EAPC 2013). The education of children nurses at all levels should encompass CPC skills and competencies.

Children's PC must also continue to be developed further at post-graduate educational level in all health related disciplines and contribute to the development of new knowledge through research. There is a need for further development of a nationally focussed and funded interprofessional educational infrastructure to deliver the end of life care required by children and their families in all settings. This includes the development and delivery of interprofessional educational programmes at MSc level.

Education provided in this area needs to be evaluated for effectiveness and utility in clinical practice.

Interprofessional education must be also underpinned by an active funded research culture to ensure data, best practice and evidence based practices are implemented nationally.

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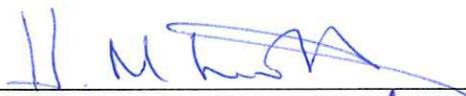
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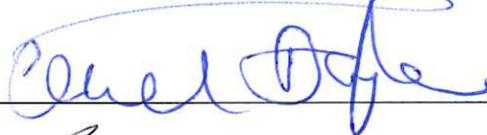
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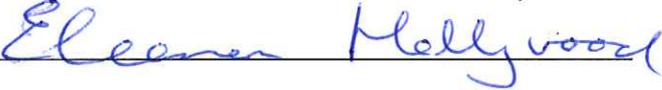
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Date : November 19<sup>th</sup> 2013

SUBMISSION TO JOINT COMMITTEE ON HEALTH AND CHILDREN

HOUSES OF THE OIREACHTAS,

LEINSTER HOUSE,

DUBLIN 2.

Palliative Care Research Group

General Discipline

School of Nursing and Midwifery

Trinity College Dublin

Professor Geralyn Hynes

Dr Elizabeth Fahey McCarthy

### **Introduction**

While a large proportion of deaths (48%) occur in our acute hospitals most deaths occur in an acute hospital. Notwithstanding the strong bio-medical focus of acute care, Irish hospitals are dealing with bed shortages, patients dying in accident and emergency departments while waiting for beds to become available, and limited if any access to single rooms for patients who are actively dying. Against this background it is not surprising that there are challenges in addressing end of life care needs of patients and their families (McKeown et al. 2010). There is international evidence of difficulties for staff from countries with different health systems that have policies requiring healthcare professionals to have basic level palliative care knowledge and skills. However, there are also factors particular to Ireland that contribute to the complexity of addressing end of life care in our acute hospitals. There are persistent inequities in palliative care service provision across regions and difficulties in policy implementation (May et al. 2013, May et al. In Press) all of which have consequences for strategies to support end of life care in our acute hospitals.

When Dame Cicely Saunders set out to develop hospice care she deliberately did so outside the NHS but with the intention of informing and ultimately bringing new knowledge and care approaches back into the health system. Though the modern hospice movement has made significant strides over the past thirty years, it is this process of embedding the principles of palliative care across different care settings that is particularly challenging despite widespread support within services and across the society.

The School of Nursing and Midwifery, Trinity College Dublin, has long had education and research interests in end of life care across different care settings. Our end of life care experiences informing

this submission are drawn from our research work with services, patients and their carers, and our engagement with colleagues.

### End of life care in acute hospitals

The greater proportion (48%) of the nearly 30,000 deaths per year in Ireland occurs in our acute hospitals. Chronic disease is responsible for most of the deaths in Ireland as in other European countries (Busse et al. 2010). We take end of life care to mean a 'continuum of palliative care and is usually used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less' (Health Service Executive 2012:4). There is now acceptance that the symptom burden or, in palliative care terms, the suffering experienced by people with advanced chronic illnesses, (such as cardiovascular and respiratory disease, dementia), is at least equal to that experienced by people with cancer. At the same time, such illnesses generally follow trajectories that allow time for adjustment, symptom management and care planning. Good end of life care in advanced life-limiting illnesses is therefore, in large part, contingent on good palliative care being introduced and delivered from as early as possible in that illness trajectory.

Ireland has rightly received recognition for the progress made in palliative and end of life care (McCarron et al. 2012, Centeno et al. 2007, Economist Intelligence Unit 2010). However, there are also well-acknowledged inequities in palliative care provision in Ireland (May et al. 2013, May et al. In Press). Specific to end of life care, palliative care policy in place since 2001 places an emphasis on the need for a basic level palliative care approach that should be embedded in clinical care across all care settings. However, attempts over the past decade in Ireland and elsewhere to bring the essence of palliative approaches to care into the acute care settings have had mixed results.

On the one hand specialist palliative care teams of doctors and nurses are now established in hospitals. On the other hand, patients who are dying do not necessarily need specialist palliative care. However, they need care that reflects the adoption of the essential principles of palliative care. Irish palliative care policy is structured to support different levels of palliative care skills and expertise.

- **Level one – Palliative Care Approach:** All healthcare professionals should have at the minimum, foundation knowledge and skills to apply palliative care principles in everyday care.
- **Level two – General Palliative Care:** At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care. Thus, healthcare professionals working in cardiac care, for example, will develop palliative care skills for their patient group.
- **Level three – Specialist Palliative Care:** Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

Establishing basic level palliative approaches to care has proven to be particularly difficult in Ireland and elsewhere (Gardiner et al. 2013, Gott et al. 2012, McKeown et al. 2010). Reasons for this are complex.

### *Conflicting philosophies of care*

Advanced chronic or life limiting illnesses are associated with disease trajectories that reflect an overall decline marked with sharp pits representing exacerbations as experienced in chronic illness. There is recovery from each exacerbation but this does not represent a return to baseline health. The dementia trajectory is associated with a gradual decline that is characterised in physical and/or cognitive frailty. Cancer trajectories are traditionally associated with a plateau followed by a rapid decline.

In the case of chronic illness, exacerbations can be life threatening and recovery unpredictable. Treatment is oriented towards management of the exacerbation as an acute event and discharge of the patient. Admission, treatment and discharge criteria, and key performance indicators in relation to organization of care centre on the exacerbation as a discrete event from a patho-physiological focus. In other words, there is a fundamental difference in this care approach and that of palliative care which takes a wider view of symptoms (Hynes et al. 2012a, Hynes et al. 2012b). Reconciling these differences in everyday care is especially challenging when key performance indicators are measured in relation to treatment and organization of care are oriented towards managing an exacerbations as an acute or discrete event.

The development of palliative care competencies for healthcare staff will go some way to ensuring knowledge and skills for end of life care across all staff involved in patient care. However, competencies on their own, will not address the need for an organization development approach to improving end of life care.

### *End of life care*

The Irish Hospice Foundation's Hospice friendly Hospitals programme has invested significant effort in supporting hospitals to improve the environment and organization of end of life care. Efforts to improve the environment of end of life care for patients in acute care have led some hospitals to designate rooms for patients who are dying. Strategies such as this need to be assessed as a potential model for end of life care.

In terms of both quality of care and costs there is now a substantial body of evidence supporting the provision of palliative care alongside care of patients with advanced life limiting illnesses (Morrison et al. 2008). However, many of our hospitals are unable to facilitate joint clinics involving palliative care because of lack of space. Moreover, evidence to support particular frameworks for integrating palliative care the Irish context is needed (May et al. 2013).

### *Recommendations*

Improving end of life care requires that palliative approaches to care be embedded in the everyday practice of healthcare professionals. This needs to be reflected in hospital service plans and key performance indicators that should be developed to specifically reflect palliative approaches to care and end of life care.

Integrating palliative care in the treatment of patients with advanced life limiting illnesses needs to be established as practice to enable care planning and especially end-of-life care plans. Models or frameworks for enhancing a palliative care approach alongside acute care need to be tested in terms of best practice for the Irish context.

The work to date on the development of palliative care competencies for healthcare staff needs to be supported by organizational development strategies aimed at supporting the provision of appropriate end of life care including advanced care planning

As a matter of urgency, evidence is needed to support initiatives such as designated wards with rooms for end of life care so that these can be assessed as possible strategies for improving end of life care and rolled out accordingly.

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Submission – End of Life Care Issues – People with Intellectual Disabilities  
Oireachtas Joint Committee on Health and Children  
Chair: Jerry Buttimer TD

## Introduction

We are pleased to add to the discussions and considerations on End of Life issues of the Oireachtas Joint Committee on Health and Children.

## Palliative Care and Intellectual Disabilities Group - School of Nursing & Midwifery, Trinity College Dublin

We are a research and practice development group that has been particularly focused upon end of life issues for people with intellectual disabilities. Our work benefits from considerable experience in services and in working with families and people with intellectual disabilities themselves, successful efforts to advance better collaboration between intellectual disabilities services and hospice/palliative care services and participation in related international activities in the U.S. and through the **Palliative Care for People with Learning Disabilities Network and the European Association for Palliative Care. Most recently Professors McCarron and McCallion with colleagues have initiated follow-up on the end of life experiences of recently deceased participants in the** Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.

Group members:

### **Professor Mary McCarron, Dean Faculty of Health Sciences**

PI - Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing – Health Research Board and Department of Health

PI – Evaluation of the Programme to Support Palliative and Hospice Care in the Republic of Ireland: The Atlantic Philanthropies

PI – A longitudinal Study of the onset and course of dementia in People with Down Syndrome – Daughters of Charity Service

PI - End of life care for persons with intellectual disabilities and dementia - Health Research Board & Irish Hospice Foundation

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Co-PI - End of life care for persons with intellectual disabilities and dementia - Health Research Board and Irish Hospice Foundation

PI - Palliative Care and Intellectual Disabilities - NYS Developmental Disabilities Planning Council

Submitted on Behalf of the Group

*Prof. Mary McCarron.*

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Professor Mary McCarron  
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## **Reflections on end of life care.**

End of life can come at any stage in the life cycle, from the womb to old age. Death is the most significant life experience that one has after birth. While death is a certainty for all human beings, few people prepare for it. Indeed in Western culture there is a denial of death. Apart from hospices, most medical institutions focus on curing the ill person and postpone death as long as possible. The dying process may be a time of stress and upset for both the dying person and his/her family. Sensitive and compassionate care is needed at each stage of the dying process. No one person or indeed no one discipline within the modern medical institution can meet all the needs of the dying person. From the medical perspective often, the focus is on curing the disease that the patient is suffering from, with little attention to the social, emotional, psychological and spiritual dimensions. Furthermore, family members are greatly impacted by the illness of the loved one and are in need of support. This proposal focuses on death in an acute hospital and how pastoral care services make a very real contribution to meeting the emotion, psychological and spiritual needs of the patient and in achieving a peaceful death.

There are three times in the process of dying when the service of a chaplain can make a significant difference; when a patient receives the news of a terminal diagnosis; secondly when the illness has resurfaced after treatment and finally at the time/ moment of death. There can be serious distress when a patient hears of a diagnosis that is

perceived as life threatening. Patients diagnosed/confirmed with a life threatening illness have been described as 'physically haywire, mentally fragile, emotionally unpredictable but spiritually dynamic.' (Kelly, 2002). Spirituality is essentially all about the essence of a person. "Spirituality is the essence of what it means to be human; spiritual issues are issues of the soul and concern our deepest values and meaning." The first task of the spiritual carer or chaplain is to affirm the personhood and identity of a patient. (Wilcock, 1996.) There may be denial, disbelief and anger on the patient's behalf. In the context of a caring relationship, the chaplain can listen to the person's story with sensitivity, acknowledge feelings without any judgement and assess the patient's spiritual and religious resources. Often the presence and attention paid to the patient is sufficient. This presence may support patients as they struggle to find a meaningful path through suffering. For some patients in Ireland, faith may become extremely important at this point, and may be supported by the sacraments or rituals of their faith community. Many patients want to review their lives to discover if their life has been meaningful. In listening to the narrative a chaplain can discern what needs affirmation and what needs resolution. Many patients need to explore their regrets and come to terms with unfulfilled parts of their lives. A caring, faithful, honest and sensitive relationship can provide the patient with the space to examine what needs exploration. Depending on the age of the patient there may be significant concern for those left behind. I recall a young woman dying, having great concern about the ability of her husband to take care of her young

children. The chaplain referred the patient to the hospital social worker who was able to work with the patient to put a plan in place for the care of her children in the event of her husband failing to do so. The last few months of this woman's life was very much focused on how she could enable her husband to take more responsibility for the care of her children. The chaplain never works in isolation but as part of the multi disciplinary hospital team so that the expertise and intervention of other disciplines are made available to the patient.

With the improvement of medical treatments, many diseases can be successfully treated and often patients will experience good health for a period of time after their initial diagnosis. Indeed many patients receive their treatments as an out-patient and only come into the hospital when there is a crisis. This is true for most oncology patients. This raises the question about spiritual support when the patient may feel isolated and alone as they struggle with their illness at home. When there is a return of the disease or a worsening of their health a patient may be readmitted to the hospital. Then a patient can experience a renewal of shock and distress. Again the presence of a caring chaplain can see and hear the pain and be able to engage with the pain as expressed. Being in solidarity with the person experiencing pain can be experienced by the person as helpful. "Those who do not run away from our pains but touch them with compassion bring healing and new strength. The paradox indeed is that the beginning of healing is in the solidarity with the pain. In our solution oriented society it is more important

than ever to realise that wanting to alleviate pain without sharing it is like wanting to save a child from a burning house without the risk of being hurt. It is in solitude that this compassionate solidarity takes its shape.” (Nouwen (1990)

A significant moment in the care of a very sick patient is when the palliative care team are brought in to provide extra support to the patient. This team have huge appreciation of holistic care and of the role of the chaplain. In caring for the dying the palliative care team and the chaplain work closely together so as to detect the presence of spiritual pain or distress . Saunders (1988) highlighted the need to recognise the concept of ‘total pain’ which includes spiritual pain. When this is recognised it is important not to medicate it but give the patient time to explore the cause of same. At times the patient is not able to verbalise what is happening. I once worked with a man, who was dying and could not communicate the cause of his obvious distress because of throat cancer. I knew that he was a catholic and that he had refused a visit from a priest. In responding to his distress I held his hand and said that I did not know what was troubling him but be assured that no matter what he did in life he was forgiven and that God was a God of mercy and compassion and he need not be afraid. Tears streamed down this man’s face and he mimed the words ‘thank you’. Often in the ministry of pastoral care a lot happens without the minister knowing the nature of the inner transformation. He died peacefully a few hours later. It is important for the chaplain and the palliative care

team to recognise that changes in a person may indicate that a spiritual experience and inner journey has taken place, and that inner peace has been found. (Saunders 2003). Another sign of this peace is when a person is grateful for his/her life and is ready to let go. It is important that the person is allowed to die. Unfortunately in some situations, families and medics refuse to allow nature take its course.

During the dying process the needs of family members and friends come into focus. They are in the process of coming to terms with the prospective loss of their loved one. Facilitating anticipatory grief is an important task of the chaplain as the family adjusts to the reality of the impending death of their loved one. Each family has their own dynamic and often issues of dysfunction that have existed in the family do not disappear when a loved one is dying. Indeed these issues may be accentuated during the dying process. While one may not change the family dynamic each member of the family can be supported and hopefully enabled to say their good- byes in whatever way they see most fitting. This does not always happen and conflict can ensue. At this point it is important that the conflict does not invade the dying process to the detriment of the patient. In recent years because of reduction in nursing and pastoral care staff there is often no one available to ensure that peace is maintained around the bedside of the dying patient. Unfortunately in an acute hospital a dying patient may not have the privacy of a room. Consequently it is more difficult to maintain

quiet and peace around the bedside of the dying person on a busy ward.

Families who are enabled to deal with the anticipated loss and death of their loved one often cope better with bereavement. Hospice provides bereavement support after a death but unfortunately very little is offered families in an acute hospital. The chaplaincy team offers a memorial service a few months after the death of a loved one. Regrettably a bereavement counsellor is no longer employed by hospitals. Offering bereavement support after the death could make a significant difference to the grieving process of those left behind, especially in cases where there is complicated grief.

The above contribution has focused on the dying patient who has been an inpatient in the hospital. Another important aspect of the role of chaplaincy is the care of families in the Emergency Department where people are either brought in dead or die shortly after admission. Dealing with the trauma of some of these deaths demands extra sensitivity and care. Presence and silent attention can contribute to the containing of the huge emotion that often accompanies tragic accidents and death. Some families request prayer and sacraments. Others do not. However, a ritual of 'saying good bye' is often appreciated by traumatised families when the person dies. In some situations the injured person may be taken to the Intensive Care Unit and presence and support is hugely appreciated as families deal with the suddenness and trauma of accidents and attempted suicides. Indeed the Intensive Care unit is a place where there could be a

chaplain assigned on a full time basis because of the acute nature of patients and the amount of distress present among family members.

In conclusion, end of life care is demanding for all those involved. Spiritual care is an important part of that care. While all professionals can offer spiritual care on different levels it is the chaplain or pastoral care provider who is the trained professional who has the skills to support and journey with the dying person and his/her family. Dying is a process; a process of healing; a process of letting go, of control, of relationships, of fear, and ultimately of life. This process differs for each patient, depending on age and personality. The presence of a caring chaplain during this journey can make a difference. Meaning can be discovered, the presence of the divine can be experienced and many patients die in peace. The presence of a chaplain can also be a support and comfort to family members and other significant people in the life of the dying person. They can also be a support to staff members who are often under pressure due to the demands of caring for many different patients in their care. At this time of cut backs in the health care system, chaplains and pastoral care personnel are more needed than ever before because nurses do not have the time to spend with the dying patient or their family.

### **Recommendations**

- 1. That ordained ministers and lay chaplains form the chaplaincy or pastoral care team.***

Currently in Ireland, Chaplaincy services are delivered primarily by ordained church ministers. Some five years ago hospital chaplaincy was provided by both lay and ordained ministers. Within the HSE moratorium on recruitment many lay chaplains have not been replaced on retirement. In Cork University Hospital two lay chaplains and the Director of Clinical Pastoral Education (CPE) have not been replaced. The CPE programme has been curtailed to one unit of three months training per year instead of the continuous programme which provided three training programmes per year. There is no longer a permanent director of CPE employed by the hospital, who not only facilitated the CPE programs but also provided bereavement counselling to many bereaved families. Consequently, for only three months of the year there are students of pastoral care available to offer engagement to all patients in the hospital. The permanent Roman Catholic chaplains are available on request, which usually means for sacramental care, and care at the point of death. This reality persists despite the changing culture and faith of patients. Not everyone entering our hospitals are Roman Catholic or Christian. Some have lost faith, others have no faith and there is a growing number who embrace faiths other than Christian. The need is for generic chaplains who are trained to meet the spiritual needs of all patients. However, it is also important to stress that when a patient requests a minister of their own specific faith community, this is respected and *honoured*.

## ***2. Chaplains specialise in specific disciplines.***

Because there are so few chaplains been employed there is no room for specialising in a specific discipline; e.g. in palliative care, in psychiatric care, in oncology, in cardiac care, in maternity or in emergency medicine. This would enable chaplains to work more closely with the interdisciplinary team.

***3. That a chaplain with training in bereavement counseling form part of the Chaplaincy team in all acute hospitals.***

Traditionally bereavement was the remit of pastoral care. This needs restoration and development.

***4. That training of Chaplains will continue and develop.***

Currently there is only one program of three months of training, taking place in Cork University Hospital. This hospital is an ideal setting for a program of CPE as the campus offers diverse and wholesome experiences for pastoral care students. The CPE program at Tralee General Hospital has ceased because the CPE Director was not replaced. Consequently there are limited opportunities for training outside of Dublin.

***5. That hospitals take more responsibility for the development of the Chaplaincy service.***

In my experience of Cork University Hospital, ordained chaplains are appointed by the Roman Catholic Bishop and accepted by the hospital without going through the usual recruitment process. Lay chaplains are required to go through the recruitment process. Also the head

chaplain need not be a priest from the diocese. The role demands expertise so there should be open competition so as to recruit the best possible person for the role.

**6. *An expansion of the palliative care team in acute hospitals is needed.***

The palliative care philosophy is about meeting the holistic needs of patients as they approach death. Their commitment to care and comfort rather than cure is appropriate for the dying patient. There is a small team of palliative care nurses in Cork University Hospital who make a significant difference to end of life care in an acute hospital. There is a need to expand this team so as to meet the needs of the growing number of patients who die in hospital.

**6. *That spiritual care provided by chaplains be extended into the community when patients are being treated as out-patients.***

The changing situation regarding the practice of faith, means that many people with serious illness, and this would include those suffering from chronic diseases like Motor Neuron and Multiple Sclerosis and other neurological diseases, do not have spiritual support available to them.

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Submission made to Oireachtas Committee on End of Life Care.

Submitted by Kathleen O'Connor. Former Director of Clinical Pastoral Education at Cork University Hospital.  
22 November 2013.

# OUR LADY'S CHILDREN'S HOSPITAL CRUMLIN

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## Submission to the Joint Oireachtas Committee on Health and Children End of Life Care

### Submission on behalf of:

End of Life Care Committee of Our Lady's Children's Hospital Crumlin, Dublin 12

### Submitted by:

Carol Hilliard, Assistant Director of Nursing / Chair of the End of Life Care Committee

### Date:

19<sup>th</sup> November 2013

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'There is no foot so small that it cannot leave an imprint on this world.'  
(Author unknown)

## Introduction

The End of Life Care (EOLC) Committee of Our Lady's Children's Hospital Crumlin (OLCHC) welcomes this opportunity to present a submission to the Joint Oireachtas Committee on Health and Children on end of life care for children and their families.

The death of a child is one of the most difficult and tragic experiences for any family to bear and its impact can have far-reaching consequences for the parents, siblings and extended family of that child. The experiences of a child and family may be very different depending on the nature of the child's death, whether it was sudden and unanticipated or expected following a period of ill-health. However, irrespective of the type of death a child may have, the service and care provided to that child and family should be sensitive, needs led, effective, equitable and respectful of the values and beliefs of the family.

The aim of this submission is to outline the current issues in end of life care for children and their families and to make recommendations for how that care can be improved. The submission will predominantly refer to the care of children with a life-limiting condition but the recommendations can largely be applied to the care of children who die from an acute or unexpected cause.

## End of Life Care Committee in OLCHC

Our Lady's Children's Hospital Crumlin (OLCHC) is the largest children's hospital in the Republic of Ireland. It is a local and tertiary referral centre for numerous national specialties and subspecialties, including for example, HaemOncology, Cardiology and Cardiothoracics, Liver Disease. In 2012, OLCHC had over 10,000 inpatient admissions and over 17,000 day care patients. Almost 35,000 patients attended the emergency department.

Approx 120 children attending OLCHC die each year, the causes of which include injury, pre-existing condition, and acute illness. Of these children, approximately 50% die in OLCHC, while the remaining children predominantly die at home and a small minority die in a regional hospital.

The End of Life Care Committee (formerly the Death Dying & Bereavement Committee) was established to promote, oversee and coordinate end of life care for these children and their families to ensure effective care and communication. The committee is a multidisciplinary committee and also has representation from parents who have been bereaved. The main aims of the committee are:

- Development and review of systems to ensure end of life care is central to the mission of OLCHC and is organised around the needs of children and their families
- Provide guidance and support to all areas of hospital planning and activity with regard to end of life care
- Development and ongoing review of guidelines, information and resources for patients, families and staff with regard to end of life care
- Identify educational and training requirements for OLCHC staff in relation to end of life care
- Disseminate resources and information with colleagues nationally and internationally

## Children in Ireland

Children under the age of 18 years account for 25% of the total population of Ireland.<sup>1</sup> While the birth rate in Ireland is reducing, it remains the highest in Europe with 71,986 children born in 2012, representing a birth rate of 15.6%.<sup>2</sup>

In 2011, 393 children died in Ireland, 65.6% of which occurred in infancy<sup>1</sup>. The predominant causes of death were 'Congenital Malformations' (31.5%) and 'Conditions of the peri-natal period' (24%). Injury and poisoning accounted for 7% of deaths in children in 2011, with boys three times more likely to die from injury than girls. In the State of the Nation's Children 2012, the cause of death in 27% of children is classified as 'Other'.

## Healthcare needs of children and families

In 1959, Platt<sup>3</sup> challenged the prevailing assumptions of the time by arguing that children in hospital have different needs to adult patients and consequently require care suited to their specific needs. Nowadays, it is without question that children have different physiological and psychological needs to adults and suffer from a different range of diseases and disorders to those commonly seen in adults, including a higher proportion of rare and often complex congenital and inherited disorders.

Therefore, while the phrase 'Children are not little adults' is frequently used in paediatric healthcare, the phrase has particular resonance when one is describing end of life care for children and their families. The number of children dying in Ireland is small, relative to the number of adults. While the principles of end of life care from the adult arena are relevant to infants and children, this group has particular needs which must also be considered and addressed. Therefore, children's healthcare should reflect the unique needs of children and their families.

## Life Limiting Conditions

The number of children who die in Ireland each year does not accurately reflect the extent of end of life care for children in the country, as many children are living with a Life Limiting Condition (LLC). The term 'Life Limiting Condition' is used to describe '*conditions for which there is no reasonable hope of cure and from which children and young people will die*'.<sup>4</sup> LLCs have been categorised into four groups to reflect the extent of the child's underlying condition and the type of possible outcome:<sup>4</sup>

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<sup>1</sup> Department of Children and Youth Affairs (2012) State of the Nation's Children: Ireland 2012. Government Publications, Dublin.

<sup>2</sup> The Economic and Social Research Institute (2013) *Perinatal Statistics Report 2012*. Health Research and Information Division, The Economic and Social Research Institute, Dublin.

<sup>3</sup> Platt C (1959) *The welfare of children in hospital*, HMSO, London.

<sup>4</sup> ACT and RCPCH (Association for Children with Life-Threatening or Terminal Conditions and their Families, and Royal College of Paediatrics and Child Health) (2003) *A guide to the development of children's palliative care services*, 2<sup>nd</sup> edn. ACT, Bristol.

Classification of Life Limiting Conditions in Children	
Group	Description
<b>Group 1</b>	Life-threatening conditions for which curative treatment may be feasible, but can fail. Palliative care services may be necessary when treatment fails or during periods of prognostic uncertainty. (Examples: cancer, irreversible organ failures of heart, liver, kidney.)
<b>Group 2</b>	Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. (Example: cystic fibrosis.)
<b>Group 3</b>	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. (Examples: Batten's disease, mucopolysaccharidoses, muscular dystrophy.)
<b>Group 4</b>	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 insult.)

*(ACT and RCPC 2003)*

As can be seen from the classification of LLCs above, a child may live with a LLC for several years following the initial diagnosis. Children with a LLC can have unpredictable outcomes and it is not uncommon for children to have multiple episodes of deterioration from which they may recover to some extent. This unpredictable trajectory of illness requires a responsive approach to care and service delivery.

It must also be recognised that children who are living with a LLC are also simultaneously continuing to develop physically, cognitively and emotionally. Therefore consideration must also be given to their needs and their rights in respect of this development, including but not limited to the right to education, the right to play and leisure, the right to have a say in issues which affect their lives and the right to access to medical care.

By applying international figures to the Irish population, conservative estimates suggest that approximately 1400 children are living with a life limiting condition in Ireland. However, a recent report from the UK indicates that the number of children with a LLC has been grossly underestimated<sup>5</sup>, suggesting that the numbers in Ireland are significantly higher. However, it is difficult to reliably establish the exact number of children living with a LLC due to the absence of a national database. A minimum dataset is being established within the HSE to capture the extent of palliative care and children with LLC in Ireland. Currently the Children's Outreach Nursing Team and the Specialist

<sup>5</sup> Fraser LK, Miller M, Hain R et al. (2012) Rising National Prevalence of Life-Limiting Conditions in Children in England *Pediatrics* **129**, e923-e929

Paediatric Palliative Care Team contribute to this database. However there is a need to ensure that all children requiring end of life care are included in the database, which will necessitate the widening of inclusion criteria.

As medical advancements continue to improve outcomes and extend life for children with a LLC, it is evident that the statistics in relation to the number of children who die each year are not solely sufficient to inform the development of services. It is important that the number of children living with a LLC is considered when planning end of life care services for children.

## **Family Centred Care**

Family-centred care (FCC) is broadly defined as promoting a partnership between the parents, family and healthcare professionals in the care of the child<sup>6</sup> and it is a cornerstone of effective children's healthcare. Central to concept is the recognition of the family as the primary constant in the child's world. The provision of healthcare to children should therefore not diminish the family's role in the child's care.

End of life care must be delivered using an approach which respects, values and supports the parents' and family's role in the care of the child. Families must be supported with respect to the decision about where they want their child to die. As the alternative is prolonged hospitalisation for children, some parents may feel that they have a moral and parental obligation to care for their children at home. However, a cautionary note is made that this sense of duty could potentially be exploited by healthcare organisations eager to vacate hospital beds<sup>7</sup>. Therefore when parents chose to bring their child with a life limiting condition home, it is critical that appropriate provision is made to support them in caring for their children at home. Home care packages need to be prioritised for children with a LLC and tailored to the needs of the child and family. The provision of home care packages needs to be equitable and the quality of the package should not be contingent on the geographical location of the child. Arrangements need to be in place to provide respite services for the child, if required by the family.

For those families who chose hospital as the place their child will die, or for families who do not get the choice, it is important that the hospital environment supports families to maintain their integral role in their child's life. Children who are dying should be prioritised to be nursed in a single room and facilities made available for parents to stay with their child. Work is currently underway to build a National Children's Hospital and children's services need to influence the design and development of the hospital to ensure the environment and facilities support children and families receiving end of life care. Furthermore provision for a bereavement coordinator must be made within the new hospital to ensure ongoing support for parents and siblings of children who have died.

Consideration must also be given to the needs of the siblings of children who are dying or who have died. In OLCHC, a bereavement information day is provided for siblings as well as for parents and this has been well received by attendees. However, constraints to services, particularly social work services, limit the extent to which this service can be

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<sup>6</sup> Smith L, Coleman V and Bradshaw M (eds) (2002) *Family-centred care: concept, theory and practice*, Palgrave, Basingstoke, Hampshire

<sup>7</sup> Glendinning C and Kirk S (2000) High-tech care: high-skilled parents, *Paediatric Nursing* **12**(6), 25-27.

provided. Palliative care services need to be adequately resourced to ensure families are provided with the support they require.

### ***Financial Implications of end of life care***

End of life care for children involved a significant financial cost for families or many parents, staying with a child in hospital requires a large financial outlay, including transport, parking, accommodation and food costs, time off work, child minding expenses for other siblings and possibly renovations to one's house to make it suitable for the child. This is particularly significant with the elimination of the Bereavement Grant. Furthermore, given the uncertainty surrounding the renewal of medical cards at present, there needs to be a prioritisation of children with a LLC to receive and retain a medical card.

### ***Communication with children and families***

Children have specific communication needs which are relevant to their stage of development. Children use their senses as a channel of communication and are adept at using non-verbal behaviour such as facial expressions and guarding to convey their feelings. As children learn to interpret non-verbal communication before they learn the meaning of words, healthcare professionals should endeavour to maintain congruence between all aspects of their verbal communication. "Play is the language of the child"<sup>8</sup> and as such is a highly effective channel of communication in the paediatric arena. Using play in its many forms, including toys, books and art, healthcare professionals can communicate explanations to children and assess the children's understanding of their experiences.

This has particular relevance when one considers that children may not be able to verbalise their symptoms or may under-report their symptoms for fear of upsetting their parents. Therefore healthcare professionals need to be supported and educated to communicate with children at all ages and to be able to identify and assess changes in children's symptoms based on subtle signs when verbal confirmation is not possible.

Healthcare professionals also need to be educated and supported to communicate with families in relation to breaking bad news and discussing end of life care. Healthcare professionals engaging in this communication need education and support to ensure it is conducted in a sensitive and appropriate way. One of the most difficult jobs for paediatric healthcare professionals is to have that difficult conversation with parents and sometimes children about end of life treatment. OLCCHC have developed a Resuscitation Treatment Agreement which guides and helps a child's primary consultant or team in relation to the discussion about certain aspects of care at end of life and the parents' wishes about this. The document aids communication among the healthcare team as it provides clarity in the final moments and ensures the patient's /parents' wishes are adhered to.

### ***Coordination and integration of care***

End of life care for children and families should be seamless, effective and designed to overcome potential barriers which could impact the quality of the child's care and as a

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<sup>8</sup> Drewes A.A. (2002) Play based interventions are needed now more than ever. *School Psychologist* 56(1), 16-18.

consequence, the quality of the child's life and death. Effective communication between all healthcare professionals involved in a child's care is essential, particularly when the child is under the care of several different specialties. In line with HIQA Safer Better Healthcare Standards (2012), a named healthcare professional should assume overall responsibility and accountability for a child's care during an episode of care. This includes responsibility for linking with other services to ensure a child receives effective, coordinated and holistic care.

Eight regional outreach nurses have been appointed to act as key workers for families and to provide a support to local primary care teams caring for children with LLCs. These roles arise from the recommendations of the national policy for Palliative Care for Children with Life Limiting Conditions<sup>9</sup>. As the numbers of children with LLC are expected to increase over time, consideration must be given to increasing this nursing resource.

The outreach nurses report through their local governance arrangements. There is no central coordination point for these nurses to ensure they are providing a similar standard and scope of care. A coordinator post could provide this support in addition to supporting their continuing professional development to enhance the role.

Due to the limited availability of paediatric pathology services, children who die in a regional hospital may be transferred to a children's hospital for a post mortem. This can cause considerable stress and anxiety for a family as they may not have any previous relationship with the children's hospital. Nevertheless, there is a need to ensure that these families have access to the full range of bereavement supports which are offered to other patients of the hospital. Effective communication and coordination between services is required to ensure these families receive seamless care.

The need for healthcare professionals to be educated in relation to communicating with and caring for children has been highlighted in many national and international reports including the report of the Bristol Inquiry (2001). End of life care for children in the community is provided by nurses and healthcare professionals who may not have received specific education and training in relation to children's healthcare. The development of a community children's nursing service would provide a valuable support and resource for the care of children with a life limiting condition.

## Recommendations

The EOLC Committee in OLCHC welcome the work of the Joint Committee in exploring the issue of end of life care and seeking to identify ways in which it can be improved. The committee makes the following recommendations to improve the end of life care for children and their families.

1. Education and training for healthcare professionals involved in end of life care for children in relation to:
  - communication with children and families
  - recognition and management of changes in children's symptoms
2. Education and information for other services in relation to the death of a child, e.g. Gardai, priests, teachers, undertakers
3. Development of a national database of children with Life Limiting Conditions - services should not be delivered solely on the basis of the number of children who have died but should also reflect the number of children living with a LLC

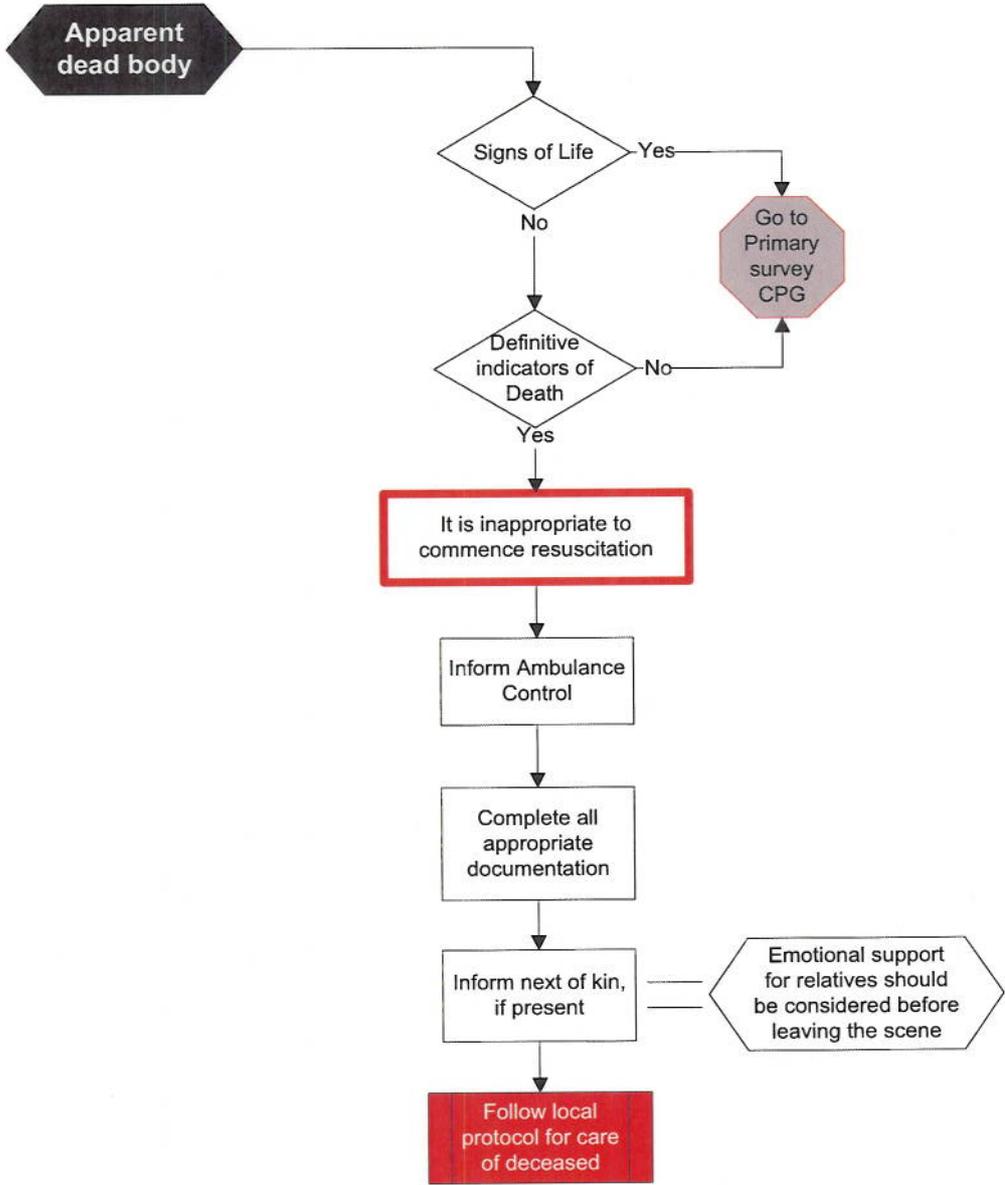
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<sup>9</sup> Department of Health & Children (2009) *Palliative Care for Children with Life Limiting Conditions in Ireland: a national policy*. Department of Health & Children, Dublin.

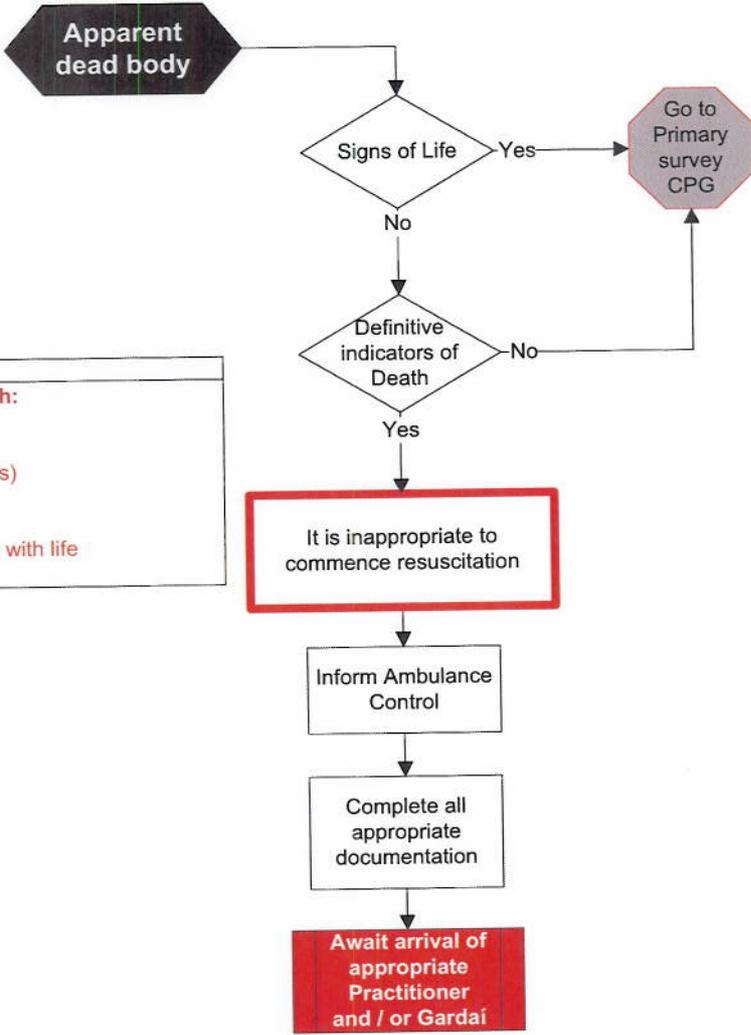
4. Development of a community children's nursing service to support the care of children in their homes
5. Support for families in relation to where they want their child to die, and the prioritisation of home care packages for those families who chose to bring their children home
6. Consideration of the financial cost of end of life care for families with priority given to the provision of medical cards for these children
7. There is a need for equity of service provision - all children and families should receive the same standard and extent of service and care irrespective of geographical location
8. Further investment in children's palliative care services to include provision of, e.g. social work services.
9. Coordination and integration of end of life care services between hospital and primary care. In addition, there is a need to ensure equity of service provision to families of children who die in one centre and have a post-mortem in another centre

## **Conclusion**

The EOLC Committee in OLCHC welcome this opportunity to contribute to the discussion on end of life care in Ireland. The recommendations made here-in are not exhaustive but support those made by colleagues in other services.

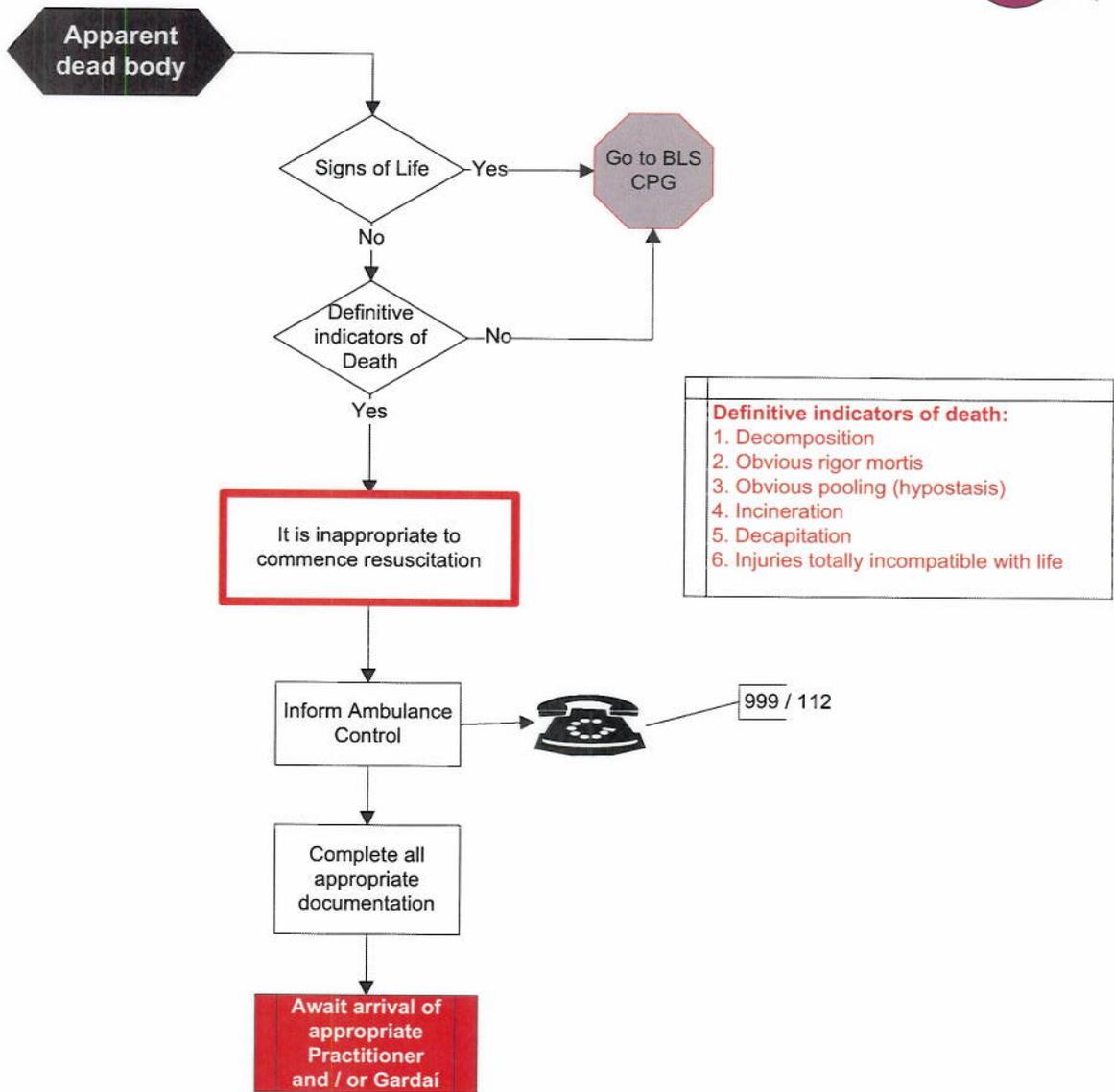


Definitive indicators of death:
1. Decomposition
2. Obvious rigor mortis
3. Obvious pooling (hypostasis)
4. Incineration
5. Decapitation
6. Injuries totally incompatible with life
7. Unwitnessed traumatic cardiac arrest following blunt trauma (see CPG 5/6.4.13)

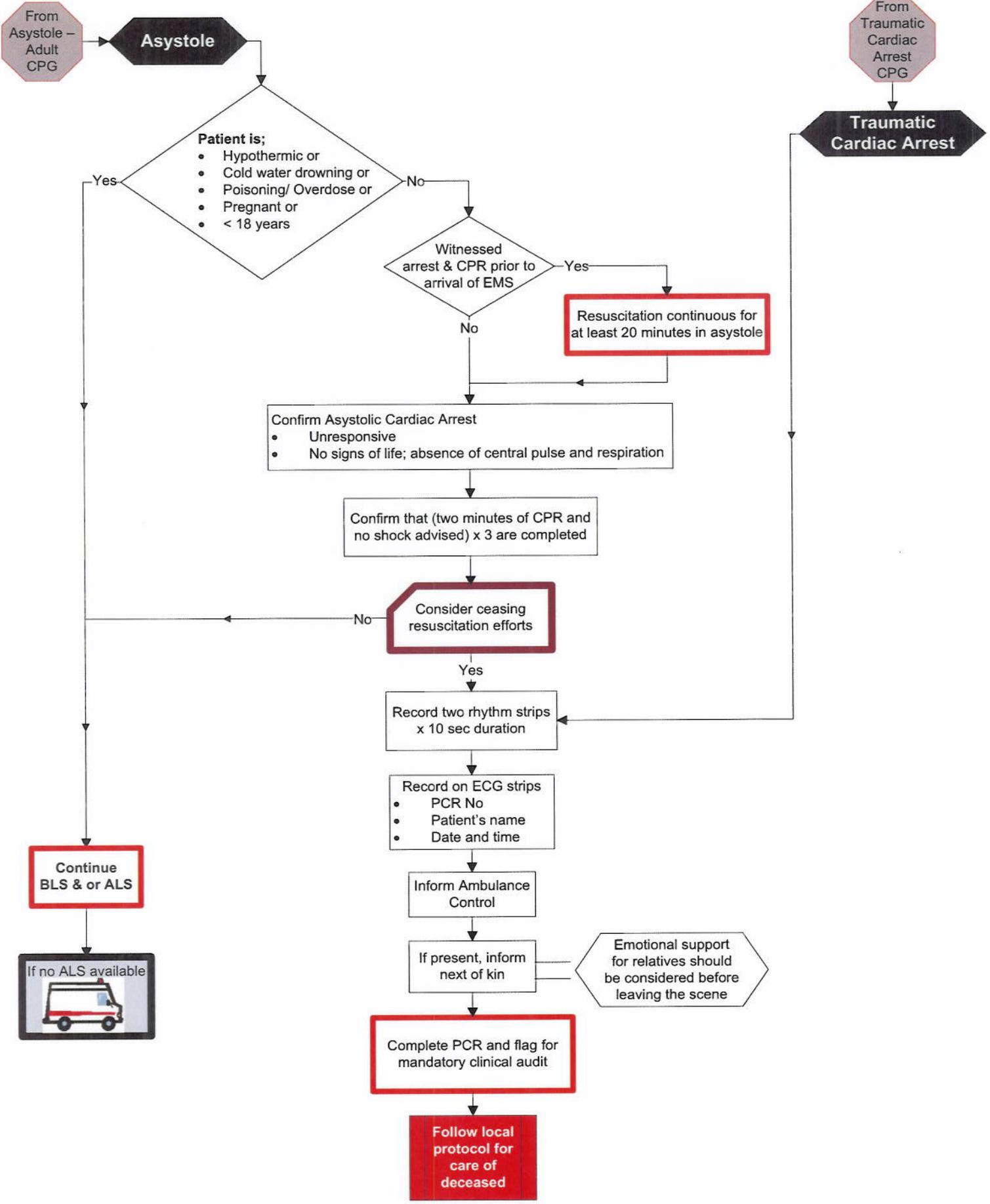


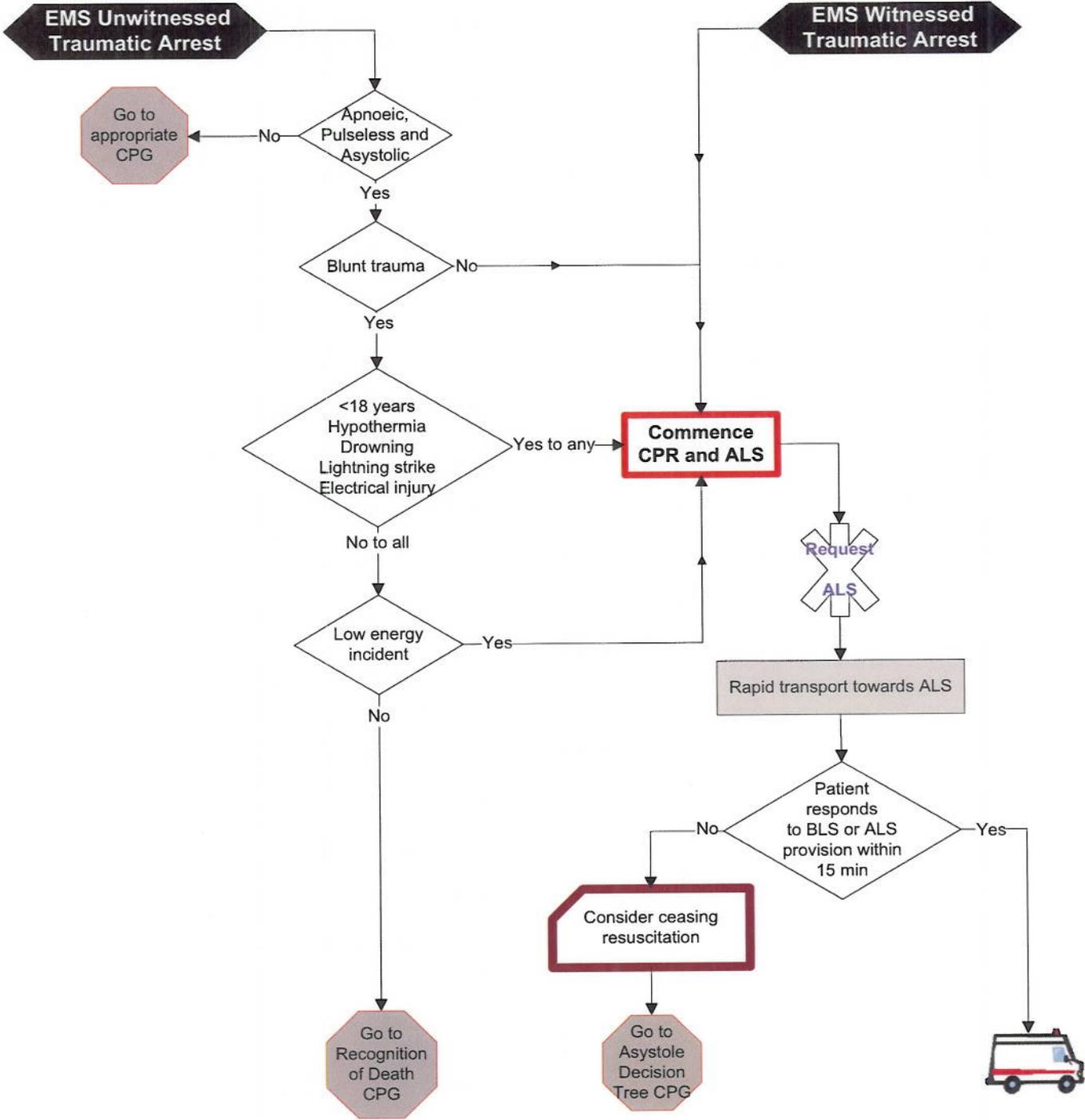
<b>Definitive indicators of death:</b> 1. Decomposition 2. Obvious rigor mortis 3. Obvious pooling (hypostasis) 4. Incineration 5. Decapitation 6. Injuries totally incompatible with life
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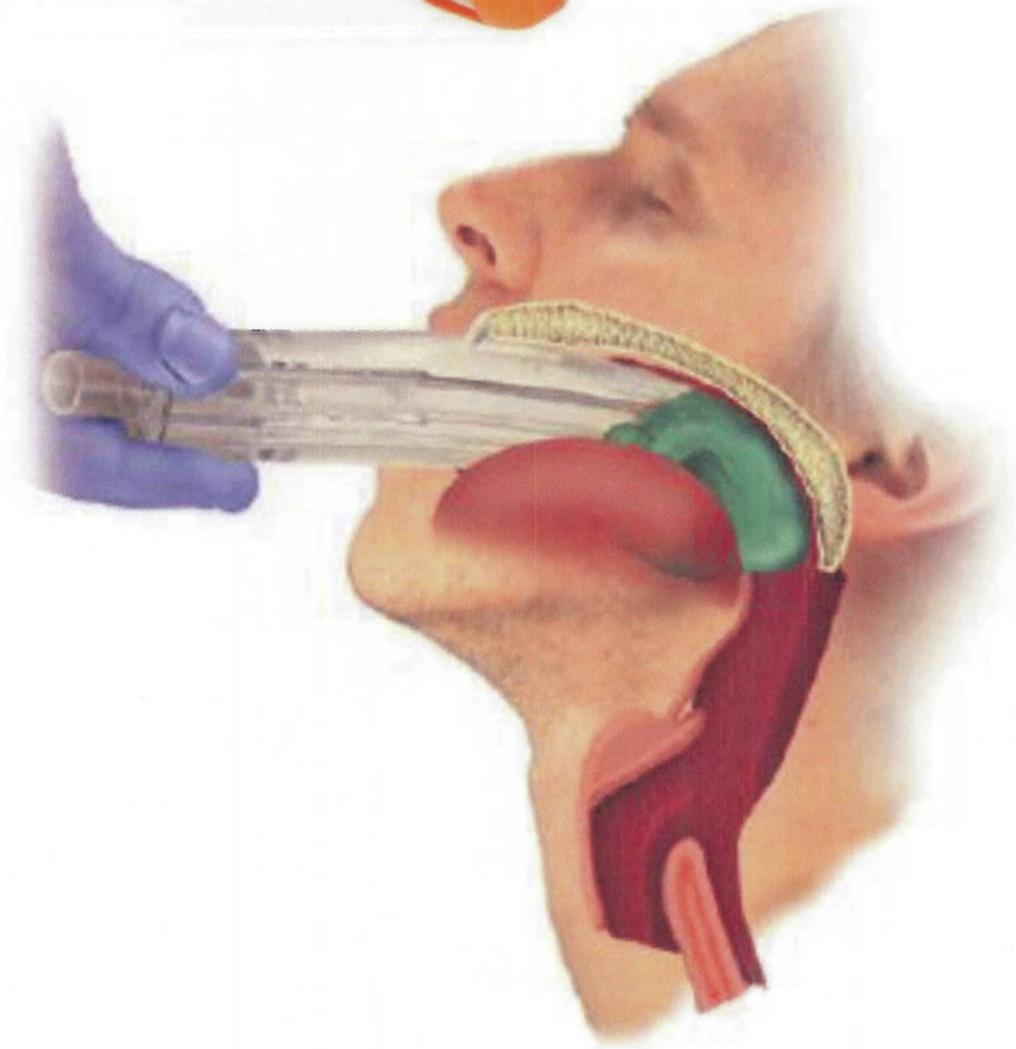
# Recognition of Death – Resuscitation not Indicated

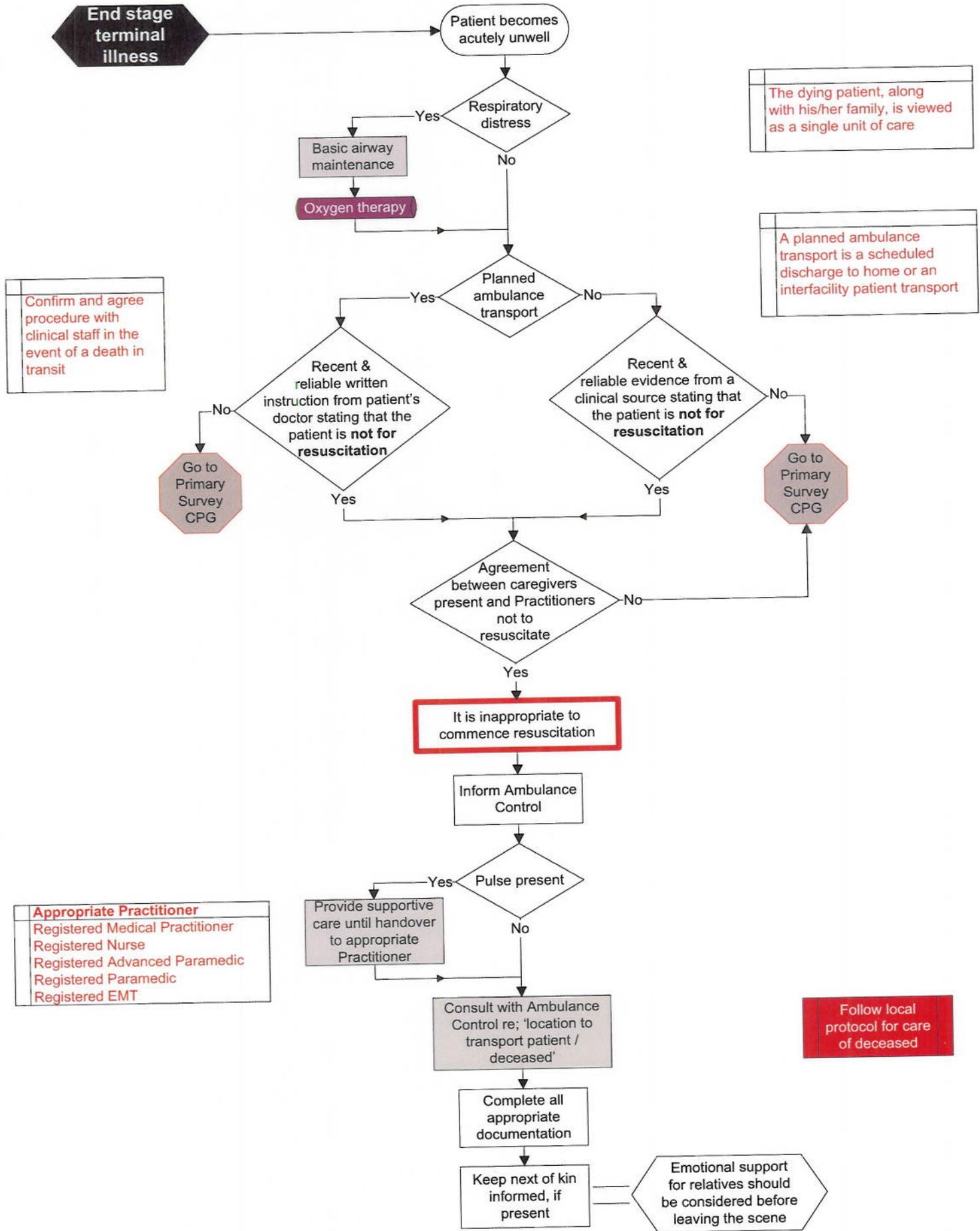


# Asystole - Decision Tree









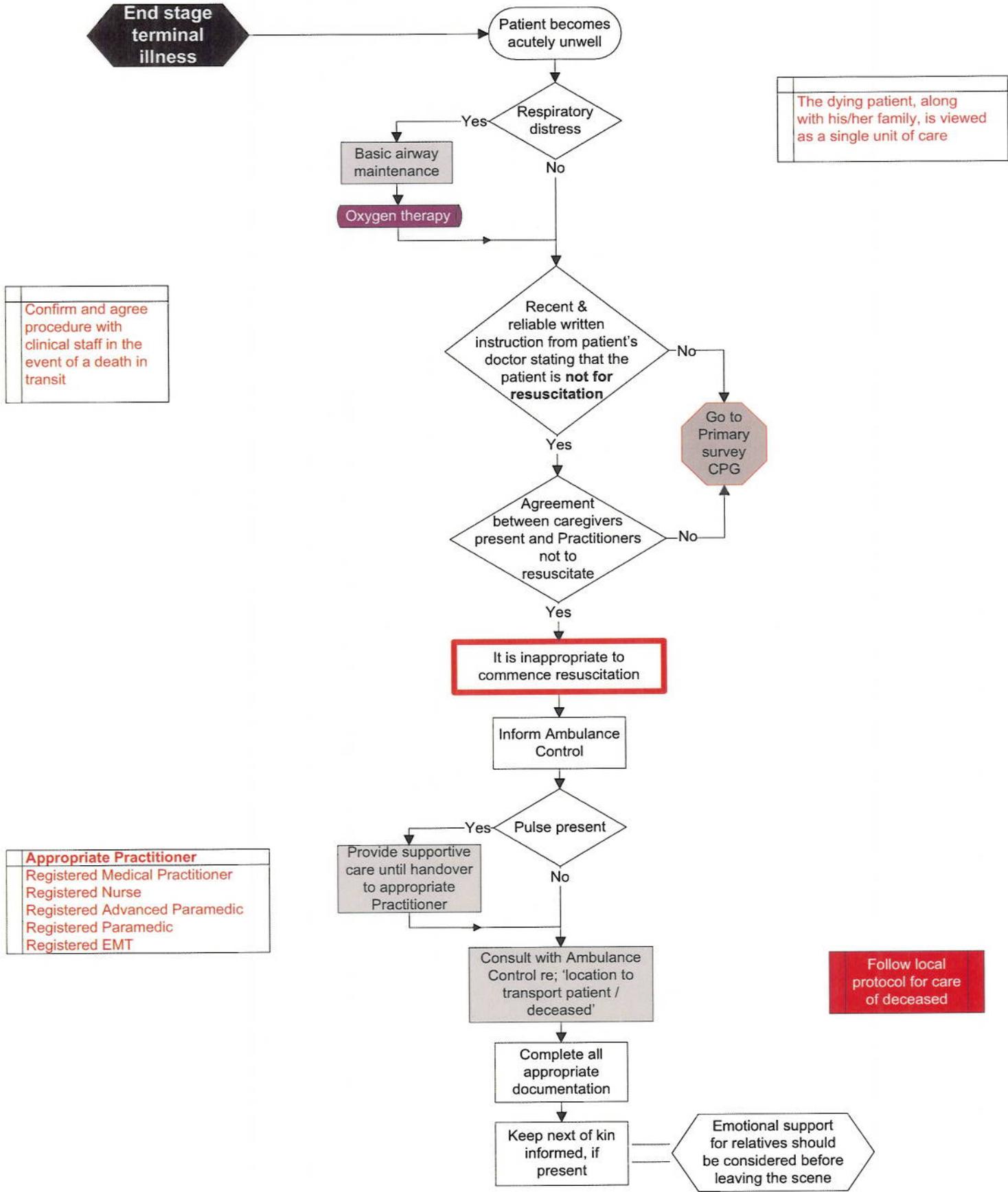
Confirm and agree procedure with clinical staff in the event of a death in transit

The dying patient, along with his/her family, is viewed as a single unit of care

A planned ambulance transport is a scheduled discharge to home or an interfacility patient transport

**Appropriate Practitioner**  
Registered Medical Practitioner  
Registered Nurse  
Registered Advanced Paramedic  
Registered Paramedic  
Registered EMT

Follow local protocol for care of deceased





# EMERGENCY SUMMARY FORM

Patient Name: \_\_\_\_\_

DOB \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

GP Name (Stamp): \_\_\_\_\_

Diagnosis: (Restrict to 3 principal diagnoses)

Year of Onset:

Management Status: (A, B, or C)\*

- |          |       |       |
|----------|-------|-------|
| 1. _____ | _____ | _____ |
| 2. _____ | _____ | _____ |
| 3. _____ | _____ | _____ |

Date completion: \_\_\_\_\_ Date review: \_\_\_\_\_

\*Management grading relates to: A = Active Management B = Beyond Curative Therapy C = Comfort Care

## FOR PARAMEDICS

Resuscitation Preferences; please indicate the option(s) most relevant to your present condition.

It has been explained to me that I would not likely benefit from attempted CPR/defibrillation, and I understand and accept this.

I do NOT want CPR / Defibrillation OR

I would like CPR / Defibrillation to be attempted, if it might be medically beneficial.

## FOR GPs AND OUT OF HOURS PROVIDERS

Key Treatment Decisions (Please also see above section on resuscitation preferences)

I would like life prolonging treatment, in order to prolong my life as long as possible.   
OR

I would like life prolonging treatments only if the treating doctors expect they will make a useful difference; if this is not the case, I would prefer Comfort Care.   
OR

I do NOT want life prolonging treatments at all. If life prolonging treatment has commenced, I request that it be discontinued, and that I receive Comfort Care, and not be subjected to Resuscitation.