



ACT

Promoting palliative
care for children

Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions





**A FRAMEWORK FOR THE DEVELOPMENT
OF INTEGRATED MULTI-AGENCY
CARE PATHWAYS FOR CHILDREN WITH
LIFE-THREATENING AND LIFE-LIMITING
CONDITIONS**

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Foreword

The ACT Care Pathway identifies the many and complex needs families have in caring for a child with life-limiting or life-threatening conditions. It presents a pathway to engage with the child's and family's needs, which can be used to ensure that all the pieces of the jigsaw are in place, so that families have access to the appropriate support at the appropriate time. The guidance can be used to identify gaps in service provision and to stimulate the development of a local strategy which will meet the needs of the local population.

The ACT Care Pathway guidance, funded by the Department of Health (England), has been written to complement the Children's National Service Framework, specifically guidance presented in the NSF module on Disabled Children and Young People, and those with complex health needs. It highlights how the requirements of the Children's NSF, in relation to children's palliative care, can be most effectively met. I am pleased to offer my endorsement and expect service commissioners to use the points identified within the pathway to facilitate discussion with providers of children's palliative care services, from both the statutory and voluntary sectors, and across all agencies and disciplines involved.

Dr Stephen Ladyman, MP

Parliamentary Under-Secretary of State for Health

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Executive Summary

- Care pathways are a relatively recent concept that have developed in response to the need for services to be more patient-focused. They have mostly concentrated on the treatment and care of people with specific diagnoses within the hospital setting. This document, commissioned from ACT by the Department of Health (England), aims to facilitate the development of integrated care pathways for children with all types of life-limiting or life-threatening conditions in all settings. The pathway aims to link children and families with community services, hospital-based services, social services, education and the voluntary sector in one joined up planning process. It is intended that the pathway should complement the National Service Framework for Children, Young People and Maternity Services (DH/DfES 2004).
- A Working Group was set up in 2003 and the group developed the structure and the potential content of the document. Members of the group produced a working draft and it was then passed to an independent consultant who devised the standards, revised and edited the text and designed the three pathway diagrams. It should be noted that the resources available for the production of the document were extremely small for such a complex and challenging task. The resulting document does not discuss the delivery of specific types of services available to children and families but concentrates on the pathway and the needs of families at points along their journey. The key aim is therefore to make children and families the focus, not services.
- The document provides a template for those working with children with life-threatening or life-limiting conditions and their families. It can be used to develop local care pathways suitable to the needs of the children they work with and can incorporate available local skills and resources. The planning of local pathways should facilitate co-operation and co-ordination between professionals and services to produce a holistic approach to the care of children and families. The vital point is that the care pathway should be jointly owned by all those involved in its design, implementation and review.
- The pathway has three sections each relating to a particular stage in the child's life. Diagnosis or recognition of a life-limiting condition represents entry to the pathway or the first stage. Living with a life-limiting condition, or the 'maintenance stage', is described in the second section. Some children may remain within this stage for months or years while others may not enter this stage at all. Thirdly, end of life and bereavement is the final stage, although it is acknowledged that bereavement is not only related to death but may be relevant throughout the child's life. The three stages are not mutually exclusive but may be used flexibly according to the particular circumstances of the child and family.
- The template sets down 5 sentinel standards along the pathway that should be developed as a minimum for families, with the aim of achieving equity for all families wherever they may live. The document, and in particular the pathway diagrams, should also be helpful to families so that they can see clearly the stages along their journey where their care should be planned and co-ordinated to deliver the support they need.
- It is inevitable that the document has a focus on health-led care since the children for whom it is intended all have a health condition with a shortened life expectancy. However, the pathway is intended to include and involve all disciplines and agencies with whom children and families come into contact, including services in the voluntary sector.
- Having one lead agency responsible for co-ordinating care is likely to ensure that the intended whole family, integrated pathway is effective for each individual family. However, it is important that agencies understand differences in terminology and assessment methods so that children do not fall between the gaps. In particular, use of the term children's palliative care may not be well understood outside paediatrics. The term 'children in need' may not be understood outside social services. Assessment tools may need to be adapted for joint use to accommodate the specific needs of this group of children and families.
- Setting down standards implies that quality improvement will become part of the implementation of the care pathway. For services that have been leading the care of these children and families for some time, measuring quality will be a natural extension of the

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work they do. However, other services or agencies may not have developed co-ordinated multi-disciplinary care and will need to use the document's standards as goals in the first instance. Those services or teams that are moving on to develop quality assurance measures will be able to provide important reference points for the network. Increasing the evidence base required to support the standards should also be an important consideration.

- Within the document there are also lists of specific goals to aim for in providing certain aspects of care within the pathway. These should be helpful to teams that are beginning to develop a multi-disciplinary service and could be used across agencies and services jointly.
- It is acknowledged that across the country there are wide variations in accessibility to services for children with life-threatening or life-limiting conditions. In particular access to 24-hour cover and support in the home is patchy. Many families do not have access to designated children's palliative care teams. It is envisaged that the template and its 5 standards could be used for the purpose of strategic planning.
- The document avoids prescribing details to be contained within the various plans advocated along the pathway. Local needs and joint planning should determine the specific content of each plan and these are likely to evolve further according to each team's stage of development and level of delivery of care. There are likely to be a variety of plans in use that are working well in different areas although the detail of these may differ significantly from place to place.
- It is acknowledged that further work is needed to identify ways of achieving continuous multi-agency service improvement.
- The Working Party hopes that this template will facilitate collaboration and partnership between families, professionals and agencies with the aim of developing new ways of working, using multi-disciplinary pathways that put the child and family at the centre of planning and delivery of care.

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1.1 Introduction to Care Pathways

The concept of integrated care pathways can be traced back to the 1980s when clinicians in the USA began to develop 'Anticipated Recovery Pathways' to define delivery of care that focused on the patient rather than the system. Interest in these tools developed in the UK in the early 1990s and by 1994 the US model had evolved into the Integrated Care Pathway (ICP) in the UK.

The development of pathways has concentrated predominantly on surgical procedures and medical conditions with a predictable sequence of events. There are now a large number of individual locally designed pathways in use in the clinical setting; for example: fracture of the femur and abdominal hysterectomy. There is an emphasis on patient-centred care with pathways seeking to improve standards and consistency of care. They aim to set down specific actions planned in sequence for the delivery of care that is appropriate for the patient, based on clinical evidence and acknowledged best practice. ICPs also provide an accepted framework against which to measure standards and prompt continuous service improvement. They invariably envisage a single point of entry by the patient to the pathway, usually from clinical assessment and subsequent diagnosis of a particular condition. Although originally called pathways they are closer to the current description of protocols. [see Appendix I].

The use of ICPs in the wider context of longer-term conditions, managed in a variety of settings and involving multi-agency input is more limited, but is nevertheless beginning to emerge. Recent National Service Frameworks are driving the development of care pathways and the need to measure standards as a means to improving outcomes of care. An Integrated Care Pathway for Early Onset Dementia was produced in the West Midlands (Saad, 2003) in response to the National Service Framework for Older People (DH 2001). It focuses not only on clinical interventions but charts also the patient's continuing care involving a wide variety of agencies outside the hospital setting.

When considering children and young people with all forms of life-threatening or life-limiting conditions as one group, the concept of Integrated Care Pathways becomes more complex and challenging. A sound evidence base is not generally

available and, although multi-agency cooperation and team working is developing, it is by no means universal practice.

This document proposes a broad generic template for developing an Integrated Care Pathway for children diagnosed or recognised as having life-threatening or life-limiting conditions. The pathway will be guided by essential standards, based where possible, on evidence. The document will be of use to those striving to improve the provision and consistency of care and support to children and families, and will assist in demonstrating the pathway from diagnosis or recognition, through ongoing care to the end of life. Children and their families will make many different individual journeys according to their own needs and circumstances, but may find the document helpful in the process. The prime intention is that this template will provide the means to develop essential components that could underpin more detailed local pathways. The document avoids discussing the many types of services available but puts children and families at the centre of a planning process, with the aim of delivering integrated services in response to individual needs.

1.2 Approach to Care of Children with Life-limiting Conditions

1.2.1 Which Children might require the Integrated Care Pathway?

Those who would benefit from the proposed Integrated Care Pathway are children with a life-threatening or life-limiting condition and their families. The fundamental characteristics are that the condition begins in utero or during childhood and is anticipated to lead to the child's premature death.

A life-threatening condition is one in which medical intervention may prove successful but by its nature carries a substantial chance of mortality in childhood. (ACT/RCPC 2nd edition, 2003). A life-limiting condition is one for which there is currently no cure available and the likelihood is that the condition will lead to the child dying prematurely (Sutherland, Hearn, Baum & Elston 1994).

In all cases the degree of threat to life will be a significant factor. Children with diabetes may not have a normal life expectancy and there may be some risk to life during periods

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of poor control, but because these risks are small these children are not included. Not all children with cerebral palsy are thought to have a life-threatening condition. Nevertheless, a significant proportion of children with severe cerebral palsy deteriorate in adolescence or early adulthood and their prognosis becomes poor. Due to the shortening of life expectancy and the impact on day to day living it is reasonable to consider these young people as having a life-threatening condition.

ACT and the RCPCH (2003) suggest that there are four groups of condition:

Group 1 Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails. Children in long term remission or following successful curative treatment are not included.

Examples: cancer, irreversible organ failures of heart, liver, kidney.

Group 2 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.

Group 3 Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.

Examples: Batten disease, mucopolysaccharidoses, muscular dystrophy

Group 4 Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death.

Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury.

It is often assumed that all life-limiting conditions proceed in a similar pattern, i.e. a steady progression. However, while some children follow a rapid fatal course from the time of diagnosis, others may follow a prolonged course of deterioration over a period of years. Some children require

constant medical attention and may frequently be in the hospital setting, whereas others may be managed in the home environment. Some conditions follow an episodic path with periods of relatively good health interrupted by periods requiring intervention, cystic fibrosis being an example. For other children the life-threatening condition may be short-lived but very serious such as extreme prematurity or severe injury. Therefore, neither the duration of the illness nor the setting is an essential element when considering the need for palliative care and the appropriateness of the Integrated Care Pathway.

1.2.2 The Palliative Care Approach

Until the 1980s the term palliative care was largely associated with the care of adults in the final terminal stages of cancer. The adult hospice movement developed an ethos of care that put the patient and family's quality of life at the centre of care. They took into account not only physical needs but also the emotional, practical and spiritual needs of the individual.

Over the last decade much work has been accomplished to promote the need for services for children with all types of life-threatening or life-limiting conditions as one group. Although many different conditions are involved it has been demonstrated that children and families have many needs in common (Mastroyannopoulou et al 1997; Lenton et al 2001). Generally speaking, palliative care has emerged within the professional field as the term being applied to the care of these children. However it is worth noting that many families, and indeed some professionals, do not recognise the current more comprehensive use of the term but associate it with the adult model of care in the terminal stage.

In considering service delivery, it is important to recognise that there are significant differences between adult and children's palliative care in both the conditions involved and the approach to care. Children are growing and developing emotionally and physically; their level of understanding will vary; their lives include the added dimension of education as a statutory requirement; they will be largely dependent on their families for their every day needs and they may have siblings whose lives will also be significantly affected. Most of the conditions are found only in children, and symptom control needs will be very different. Those delivering care to

children and young people should be trained specifically in their care, as recommended by the report from the Kennedy Inquiry (2001).

In addition, children's rights and principles of care will be enshrined in different legislation from that of adults. For example, the 1989 Children Act, Children (Scotland) Act 1995, Children (Northern Ireland) Order 1995 and the UN Convention on the Rights of the Child all underpin the care of children and therefore the delivery of services will be required to reflect these.

1.2.3 Definition of Children's Palliative Care

As the need for palliative care for children has been increasingly acknowledged it has become important to define what is meant by the term. In the past, palliative care related to symptom control in the last days of life, while today it is more widely perceived as multi-disciplinary whole family care, ideally from the point of diagnosis or recognition of a life-threatening condition.

The definition promoted by the ACT/RCPCH Guide to the Development of Children's Palliative Care Services (2003) says:

Palliative care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite, and care following death and bereavement. It is provided for children for whom curative treatment is no longer an option and may extend over many years.

ACT / RCPCH (1st Edition 1997)

1.2.4 Philosophy and Principles of Children's Palliative Care

In many ways the broad approach to palliative care is synonymous with the core values of all services to children. This would include being open, honest, respectful, working in partnership with patients and families, delivering high standards of service, communicating effectively and working proactively with other disciplines and agencies.

Children's rights have been developed and widely promoted in recent years. The national and international legislative framework will therefore inform any philosophies surrounding the care of children. Added to these are the standards contained in the National Service Framework for Children, Young People and Maternity Services (2004) and the important green paper 'Every Child Matters' (England 2003) in which the Government set down clear direction for the delivery of services to children.

When considering principles more specific to children's palliative care, the 1994 ACT Charter for children with life-threatening conditions set down 14 principles of appropriate care for families that have since been used widely in service development. [see Appendix II: revised version 2004]. The ACT/RCPCH Guide (2003, 2nd Edition) included principles for commissioning services such as inter agency planning, flexibility and choice for families, continuity of care, and staff with training and expertise. Children and their families need to be involved in all stages of decision-making involving their care and treatment. They should be acknowledged as experts in the care of their children and should be encouraged to work in partnership with professionals as part of the team.

This combination of sources makes it possible to suggest a set of principles to be applied to children's palliative care:

Principles for Children's Palliative Care

- Care should be child and family focused and should take account of children's rights
- Care should encompass symptom management, emotional support, practical support, spiritual needs and bereavement for the whole family, and should respect cultural and religious differences
- Service delivery should be based on assessment of needs starting as soon as possible after diagnosis or recognition
- The delivery of care should be well co-ordinated, with an emphasis on continuity of services
- Care plans should be flexible to accommodate changing needs and choices
- Regular review of needs should be undertaken and care plans adjusted to take account of changes in circumstances

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1.2.5 Multi-agency Commissioning

The objective of multi-agency commissioning and delivery of services is to ensure resources are spent wisely to achieve the maximum impact on health and well-being. Increasingly it is recognised that commissioning and provision of services should not be separated, and that quality service delivery requires a good working relationship between those holding the resources, those delivering the services and those receiving the services.

The importance of multi-agency commissioning in support of children with life-threatening or life-limiting illnesses and their families cannot be overestimated. By 2006 the majority of districts in England will have Children's Trusts for commissioning services across all agencies. Under the new Children Act (in progress) the remainder will be required to be in place by 2008. A small number are now being piloted as a method of achieving multi-agency co-ordination but the results from their evaluation will not be available for some years. Local Strategic Partnership Boards or their equivalents are likely to be the predominant structure for multi-agency planning in the medium term but further changes are possible.

1.3. The Potential of Integrated Care Pathways

1.3.1 What are Integrated Care Pathways?

An inevitable consequence of locally managed healthcare is that there are often differences in practice between different clinicians and organisations, leading to wide variations in both patient care and outcomes. In addition, limited resources can affect the ability of staff to deliver optimal standards of care.

The development of National Service Frameworks, the emphasis on evidence-based practice and the rigours of quality improvement, have increased the need for services to be accountable. As part of the national agenda for improved services, these measures are seen as key in the delivery of better quality of care for the patient.

A natural extension of this trend has been to devise protocol-based care that sets down in detail the clinical interventions for a given medical condition. Integrated Care Pathways (ICPs) develop this theme further by incorporating national evidence-based standards, multi-disciplinary collaboration, anticipated sequential care, and rigorous clinical and

administrative record-keeping to include variations from the pathway. The patient is at the centre of the pathway with care adapted to the patient's individual needs. In this way care can move from being based around an organisation's structure to being viewed as a patient's journey in linear form, with professionals and services moving onto and off the pathway as required.

Integrated Care Pathways are therefore both a concept and a tool. They include a number of elements:

- A structured plan of care setting down objectives and stages of care
- Evidence-based guidelines
- Clinical and administrative documentation for all disciplines involved in delivering the care
- A system for reviewing performance and variations
- Measurement of outcomes
- Quality improvement by capturing data on variations from planned care
- An evolutionary tool to promote continuous quality and service improvement (de Luc, 2001)

This move towards patient-centred care has developed in various countries and a number of alternative names are being used, such as critical pathway, care protocol, patient pathway and care map.

The variety in name and therefore definition can cause confusion. However, the terms 'Care Pathway' and 'Integrated Care Pathway' appear to be the two being adopted most commonly in the UK (de Luc, 2001).

The National Pathways Association was established in 1996 to support the development of care pathways. The definition agreed by its 300 members states:

An Integrated Care Pathway determines locally agreed, multidisciplinary practice based on guidelines and evidence where available, for a specific patient/user group. It forms all or part of the clinical record, documents the care given and facilitates the evaluation of outcomes for continuous quality improvement

National Pathways Association

However, the pathway proposed in this document goes further than is suggested by this definition.

1.3.2 Developing Integrated Care Pathways

Historically, care pathways have been developed almost exclusively for clinical care. However, ICPs could potentially cover all healthcare situations including hospitals, community services, primary care and home care. Equally, although they have evolved in the field of health, the principles of ICPs are relevant to other fields such as social services and education. The use of ICPs as multi-agency tools should streamline the patient's journey and avoid duplication or omission. They should clarify roles and responsibilities, encourage multidisciplinary collaboration, work to common standards of practice and ensure that care is patient-centred. Patients would benefit from having an outline of the anticipated plan of care and from the resulting improved communication between professionals delivering the care.

Using ICPs across boundaries requires multi-agency understanding of the concepts as well as co-operation and commitment. A number of critical factors require consideration to increase the likelihood of successful implementation of a Care Pathway. There should be organisational support for the pathway and this will require commitment by senior management in all agencies and settings involved. Pathways should be seen as a vital part of an organisation's quality improvement programme. The pathways should be developed and 'owned' by those who will use them. Documentation needs to be user-friendly and methods for variance analysis need to be included. Record-keeping, confidentiality and data protection will require careful consideration.

In the literature, development of Integrated Care Pathways is described in various stages (de Luc, 2001). A steering group involving senior executives and key stakeholders is advised. The first stage involves the design and adoption of the pathway for a specific client group. At local level this requires a review of current practice involving both professionals and patients. As a result of the review it should be possible to identify the improvements necessary. Wherever available, evidence-based practice and national standards should be embedded in the pathway.

The second stage of the ICP is its implementation and use with the client group. There will be a focus on the use of the documentation to deliver the agreed pathway of care.

Professional freedom can be exercised in the delivery of care and variations can be implemented according to the needs of the individual patient. The action and the reason for the variation will be recorded.

The third part of developing an ICP is the ongoing review of the pathway. There will be critical review of its use and analysis of the variations. This part will ensure that the pathway is responsive to the needs of the patient and that there is continuous improvement in the delivery of care.

Elements of an ICP may include national standards, local protocols or protocol-based care [see Appendix I].

1.3.3 Potential of ICPs for Children with Life-threatening Conditions

It has been accepted since the mid 1990s that most children with life-threatening or life-limiting conditions and their families, while having different diagnoses, will have many needs in common (ACT Charter, 2004 4th Edition). The diagnosis of a life-threatening illness in a child has a profound impact on all aspects of the child and family's lives. The concept of a holistic approach to the delivery of care was promoted in the ACT/RCPCH Guide to the Development of Children's Palliative Care (2003) and this concept has been embraced by a growing number of multi-disciplinary teams caring for these children. However, the reality for a large number of children and families who do not have access to such a team is that they encounter bureaucratic boundaries and a lack of communication between professionals who are delivering aspects of their care. In a survey of families (ACT 2003), better co-ordination and continuity of care was identified as an important need.

The development of Integrated Care Pathways for this client group would appear to be an ideal step in the direction of more effective and equitable services. The National Service Framework for Children (DH 2004) recommends the use of journeys, pathways and networks to transform the delivery of services to families to address the common problem of discontinuity. Whilst it is acknowledged that ICPs for these children will be difficult to define in great detail due to the disparate range of individual conditions, a broad template for a generic pathway, encompassing common needs, is likely to be helpful. The greatest challenge will be eliciting a commitment to the pathway by professionals from different

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agencies, with different budgets and priorities, and with different levels of understanding of the needs.

The first step to achieving this goal may be to develop local strategic planning groups to encourage all disciplines and agencies to work together to acknowledge the needs of this client group and develop a unified strategy for care. In some parts of the country this is taking place [e.g. East Sussex, Brighton & Hove]. In other areas there are already specialist multi-disciplinary teams working in the community as the lead for the care of these children [e.g. Lifetime Service, Bath]. In other places, teams based within Child Development Centres may be the focus of multi-disciplinary care. There will be a need to work across all the boundaries with senior managers from hospitals, community services, social services and education to agree care pathways that are practical and achievable.

The benefits to children and families of local Integrated Care Pathways are likely to be:

- Early assessment of needs, preferably immediately following diagnosis or recognition
- Inclusion on the caseload of a multi-disciplinary team
- Better co-ordination of care and communication between professionals and agencies
- A structured plan that anticipates care needs and is supported by standards and quality assurance measures
- Care that is child and family focused
- Regular review of needs
- More effective use of resources and less risk of duplication or omission
- Empowerment of children and families at the centre of the plan through information
- Better equity of care between different disease groups and geographical areas
- A defined workforce planned for the effective delivery of care with one agency clearly identified as taking the lead

The extensive range of conditions involved and the wide variety of circumstances surrounding diagnosis and prognosis means that a single point of entry to the Integrated Care Pathway is unlikely to be possible for all families. It is also likely to prove difficult to incorporate time frames for many of the activities. The Care Pathway template suggested in this document is divided into three parts – diagnosis or recognition of the life-limiting condition, maintenance or

intermediate care, and end of life. The three pathways are not inter-dependent and can therefore be used either separately as a single plan, or together in sequence, as appropriate. Families should be able to enter the pathway at any stage but each of the three sections highlights a key activity as a starting point. Some families may move immediately from Pathway 1 (diagnosis/recognition) to Pathway 3 (end of life), while others may remain on Pathway 2 (living with LTI) for many years.

Where a detailed Care Pathway or protocol has been devised for clinical care associated with a particular disease or condition, it can be used alongside the generic pathway thus ensuring the inclusion of all the additional elements needed for a comprehensive multi-agency pathway.

1.3.4 Standards and Quality Improvement

In recent years there has been an increased emphasis on continuous service improvement ranging from the 'Patients' Charter' to clinical governance. Over the years the focus of quality initiatives has changed from an emphasis on organisational structure to concentrate on the experience of people or 'users'. The Department of Health has established an agenda for quality improvement through national governing bodies and National Service Frameworks.

Quality is a degree or standard of excellence. It is a subjective concept and for this reason the perception of quality may differ between a range of interested people – practitioners, managers, commissioners, politicians, patients, and carers. Quality is usually measured against a standard and therefore quality improvement is the process of verifying that what was intended when the standard was set has actually happened with the desired outcome. It is about making sure the right things happened to the right people, at the right time, in the right way, in the right place, with the right staff and resources.

The use of ICPs is likely to play an important part in supporting the quality agenda, but it is essential that continuous monitoring and review of quality is an integral part of the process so that the necessary improvement can be made.

Principles for the development of Integrated Care Pathways

- They must be developed and 'owned' locally by a multi-disciplinary team
- They can cross organisational and inter-agency boundaries
- They include a plan of anticipated care for an identified group
- They make the patient the focus and allow for variation when appropriate
- They incorporate evidence-or research-based standards or guidelines
- They include systems for rigorous record-keeping
- They include measurement of outcomes and promote continuous quality improvement

Part 2 | The Integrated Care Pathway

2.1 Pathway

The Integrated Care Pathway in this document is proposed as a broad outline of the key events that happen, or should happen, in the journey made by children and families. It is divided into three stages:

- diagnosis or recognition of a life-limiting condition
- ongoing care that may last for weeks, months or years
- end of the child's or young person's life, including bereavement care

Each of these stages is shown beginning with a key event that is vitally significant to the family. In the linear diagrams these are shaded dark blue.

In its entirety the pathway promotes five sentinel standards and these will be described in more detail in the following sections. They identify the weakest points for many families in their patterns of care. These are the points at which there are often difficulties with communication and integrated working by professionals and are therefore key actions that should be given the highest priority. In simple terms they set down the minimum that every family should expect during their journey. If they are adopted nationally, in time they should provide the means to a more equitable system of care. They are:

1. The prognosis – breaking bad news
2. Transfer and liaison between hospital and community services
3. Multi-disciplinary assessment of needs
4. Child and family care plan
5. End of life plan

While the pathway in this document suggests a broad template, it is likely that those at local level will need to develop their own pathway and delivery plans to take account of existing local services, available resources, and geographical area. To assist in this process each of the three pathway sections has included goals that are intended to provide helpful guidance. Some of these goals may be based on evidence while others may be borne out of the experience of providers currently working with families.

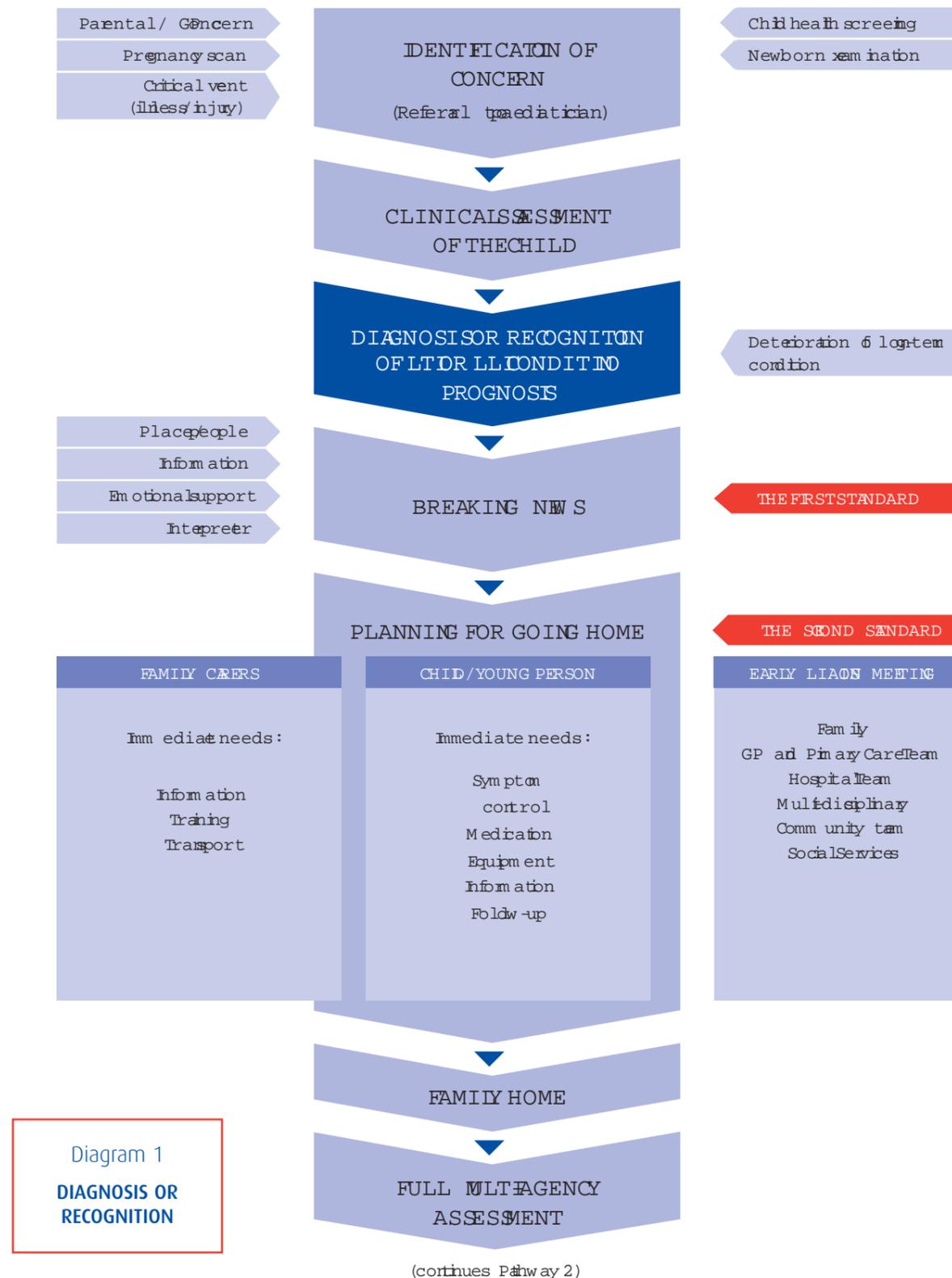
2.1.1 Entry to the pathway

The start of the journey for many children (Diagram 1) is likely to be attendance or admission to hospital following a professional concern, a parental concern or a critical event, although this may not always be the case. It is important that all children have equal access to high quality medical assessment in order to achieve the best possible chance of a diagnosis. Medical assessments are likely to involve investigations and contact with a number of different professionals before any diagnosis is made. Whilst the authors acknowledge that good practice at this initial stage is applicable to all children receiving a medical assessment, it is worth noting here some of the key points. (NSF Standard for Hospital Services 2003)

- Services should be child and family-focused
- Care should facilitate access to play and education where possible
- Concerns and anxieties of families, including the child should be heard and responded to
- Families should have access to an appropriate specialist and should have the opportunity for a second opinion if requested
- Fully informed consent should be sought for investigations and results should be communicated promptly
- Practical assistance should be offered and available such as transport, accommodation, interpreters
- The importance of family members in the child's life should be respected and ethnic, religious and cultural needs should be taken into consideration

For families in these circumstances the Integrated Care Pathway will begin clearly with the devastating news that a child has been diagnosed with a life-threatening or life-limiting condition. For most, the diagnosis will usually be given a name. Breaking this news to the family will require great skill and sensitivity.

However, for a significant proportion of children, final recognition of the likelihood of premature death may come some considerable time after it has been found that the child has a health condition. For some there may or may not be a named diagnosis. For others, the diagnosis in itself may not be an indication that the child has a life-limiting condition, for example cerebral palsy. For yet other children it may be the point at which all attempts to prolong life have failed. The



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important element will be that there has been deterioration to the extent that it has become increasingly evident that the long-term prognosis is poor.

Some children never receive a diagnosis and this lack of a named condition can leave the family in limbo without legitimate access to appropriate services. Although there may not be a clearly defined diagnosis, it may be that the paediatrician has identified a shortened life-expectancy but feels reluctant to discuss this with the family. At the point when it has been recognised that the prognosis is poor for a child with a previous health condition, whether named or not, this recognition should be communicated to the family with the same degree of care and sensitivity as those children for whom the prognosis was clear from the start.

At whatever stage the diagnosis or recognition is made in the child's life, the start of the pathway is likely to be relevant. How families proceed along the pathway will then depend on each individual set of circumstances. The key is that the family is aware that the child is life-limited and breaking this news marks the first important milestone on the pathway. Some families may then proceed immediately to the final stage in the pathway while others may need to be supported through multi-agency needs assessment and long-term care plans.

2.1.2 Breaking News: THE FIRST STANDARD

Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided both for the child and the family in language that they can understand

Breaking the news to a family that their child is expected to die prematurely is undoubtedly one of the most difficult tasks that any professional has to face. In spite of efforts to improve this area of care, many parents are still treated clumsily or insensitively and the experience lives with them for a very long time (Scope 1994). At such a difficult time families need honesty, respect and, above all, time from professionals disclosing the diagnosis or prognosis. If disclosure is avoided or postponed, parents are likely to stumble on the truth at a later stage and their trust and confidence in professionals is damaged. Research also confirms that both children and parents need information at this stage and in language that

they can understand (Sloper and Turner 1993). However, written information should be used as a back-up to face-to-face discussion not as a substitute for personal communication. Providing details of support groups at the earliest possible stage is also beneficial to families who often feel a sense of isolation following the starkness of a diagnosis. Contact a Family is an organisation that provides information on parent support groups.

From the time of diagnosis parents and professionals should recognise that they will be entering into partnership in caring for the child. In addition, the training and preparation of staff who will have to handle this situation should be a high priority. Appropriate guidelines should be devised using established good practice.

Key goals in breaking bad news

Good practice in breaking bad news has been described by SCOPE (1994):

- Plenty of time should be made available for a face-to-face discussion, including opportunities to ask questions at the time and subsequently
- A place should be provided that ensures complete privacy
- Parents should be together to receive the news; if not possible, every effort should be made to ensure that another relative or a friend is present to support the parent hearing the news first
- Helpful written material should be provided as a supplement to, but in no circumstances a substitute for, direct communication
- Information should be conveyed in readily understandable language, using an interpreter where necessary.

The ACT Charter (2004) also states that:

- Parents should be treated with openness and honesty
- Parents should be acknowledged as experts in the care of their children.
- The needs of the child or young person for information appropriate to their age and understanding should also be taken into account.

2.1.3 Planning for going home: THE SECOND STANDARD

Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.

It has long been recognised that home is usually the best place for children and that they should be admitted to hospital only if the care they require cannot be provided at home or on a day basis (DH 1991). Following a diagnosis in hospital there is likely to be an aim for the child to return home as soon as possible. The timing of this will depend on whether or not there needs to be hospital treatment of the child's condition.

However long the stay in hospital, the point at which the child returns home represents another significant event on the pathway. This is often a time when communication can break down and a detailed handover to community staff is not always achieved successfully. The pressure on beds and hospital staff is undoubtedly a factor and sudden decisions to discharge home can present difficulties both to families and to those in the community who may not be aware of the child. This can also apply to children whose diagnosis is confirmed in an outpatients' clinic.

The National Service Framework for Children emphasises the importance of discharge planning (Standard for Hospital Services 2003). Taking a child home with a life-limiting diagnosis, sometimes with complex medical procedures to follow and possibly with medical equipment, is a truly daunting task. Careful planning for this critical transition is vitally important.

Going home from hospital will require an initial needs assessment meeting in the hospital involving key hospital staff, community staff, social services and the family. Some GPs appreciate being involved at this stage and it should be a goal that GPs are invited to be part of the transfer process. The hospital team will provide vital input to the discharge planning. Ongoing liaison between hospital and community teams will be important in the future care of the child. In some cases the hospital may provide an outreach service. A number of needs should be discussed and agreed to enable smooth transfer to home such as training in complex procedures, availability of equipment, pharmacy supplies, and

transport. Clear lines of communication should be agreed and the family should be able to call for help on a 24-hour basis. It may be possible to identify a key worker at this stage.

Key goals in planning transfer to home and community

- Community Services should be notified as soon as practical
- There should be community in-reach to the family in hospital, in person wherever possible or via telephone
- Planning should begin as soon as possible and a clear plan for transfer should be agreed with child, family, hospital and community services
- A lead community children's nurse should be agreed before transfer, the child's GP should be invited to become involved and clear plans should be in place for shared medical care
- Equipment and supplies should be provided before transfer
- Training should be provided for carers before transfer
- Clear lines of communication should be agreed
- A home visit should be arranged within 3 days of transfer
- 24 hour contact number should be provided to the family
- Where possible a key worker should be identified

2.2 Pathway 2: Living with a Life-Threatening or Life-Limiting Condition

Whether the child's condition involves active treatment or not, care and support will move from the immediate and intense activity surrounding diagnosis or recognition to what is often called 'the maintenance phase'. (Diagram 2) This is the ongoing care that will be required, extending for weeks, months or even years. It will involve a return to some sort of 'normal life' although most families will say that life is never 'normal' after such devastating news about their child. The reality is that the whole family is living with a life-threatening condition and all the demands and painful experiences that come with it.

The common theme of this stage is that care tends to be based around the home. This is the time when parents may be

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particularly vulnerable. They may become isolated, and over time may suffer exhaustion, stress or depression. Many find that once home they are simply expected to get on and cope.

‘There are lots of people all at once telling you things you have to do and places you have to get in touch with. But nobody has helped me live day by day with every day worries about surviving all your debts and all the physical problems and also the emotional worries you have. You’re sort of left in limbo hoping someone will tell you who there is out there to help you.’

(Voices for Change: ACT 2003)

Throughout the child’s illness a wide variety of health, social services, education and voluntary agencies will become involved. Many families have found they have to organise and co-ordinate all these activities themselves and must repeat their situation to numerous different professionals over and over again.

‘The simplest things always seem a battle – getting in touch with the right person, explaining the situation, and then waiting for them to call back.’

(Voices for Change: ACT 2003)

The key to ensuring that families receive the right support at the right time is for one agency to take the lead role and to work in partnership with the child and family, enabling them to take control of their situation and helping them access the various services they need. In recent years the development of the specialist multi-disciplinary community team has been ideal in fulfilling this role. For many children the child development team or the community children’s nursing team provide the central role. These teams will help to co-ordinate care for the child and family. Where appropriate the hospital will also play an important part in the co-ordination of care, providing a vital link with the child’s consultant and other key staff.

In order for these lead teams to help families access the care and support best suited to their individual situation, it is essential that a full assessment of the child and family’s needs takes place. This process should begin as soon as possible after the diagnosis or recognition of a life-limiting condition and should be multi-disciplinary and multi-agency, involving assessment of health, psycho-social, practical and educational needs.

2.2.1 Multi-agency Assessment of Family’s Needs: THE THIRD STANDARD

Every family should receive a multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals

Since the 1989 Children Act [also Children (Scotland) Act 1995; Children (Northern Ireland) Order 1995] there has been a duty to assess the needs of children in need. The ‘Framework for the Assessment of Children in Need’ (DH 2000) provided practical guidance to social workers and others on the assessment process for children in need, particularly for children at risk. This model uses the triangular format that has become a familiar tool among social workers. The ‘Assessment of Children with Life-limiting Conditions and their Families’ (ACT 2003) sets out guidance more specific to this group of children, providing detailed information on planning, record-keeping and the processes involved in assessment. A common assessment framework is currently in development.

Assessment of the family’s needs involves in-depth gathering of information, with the child and family at the heart of the process. It has been defined as:

Definition
Assessment is a discrete process resulting in understanding of need from which a plan of action can be developed
 Framework for the Assessment of Children in Need: DH 2000

Assessment of needs as soon as possible after diagnosis or recognition. The importance of the family needs assessment stage cannot be understated as it forms the introduction to the care team that will play a central co-ordinating role, and is an important foundation for building trust, partnership and support for future care. For most, the care of the child is likely to focus on the home, although for some children the hospital is likely to continue to play a major part. A comprehensive, whole family needs assessment process should begin as soon as possible after diagnosis or recognition of a life-limiting condition.

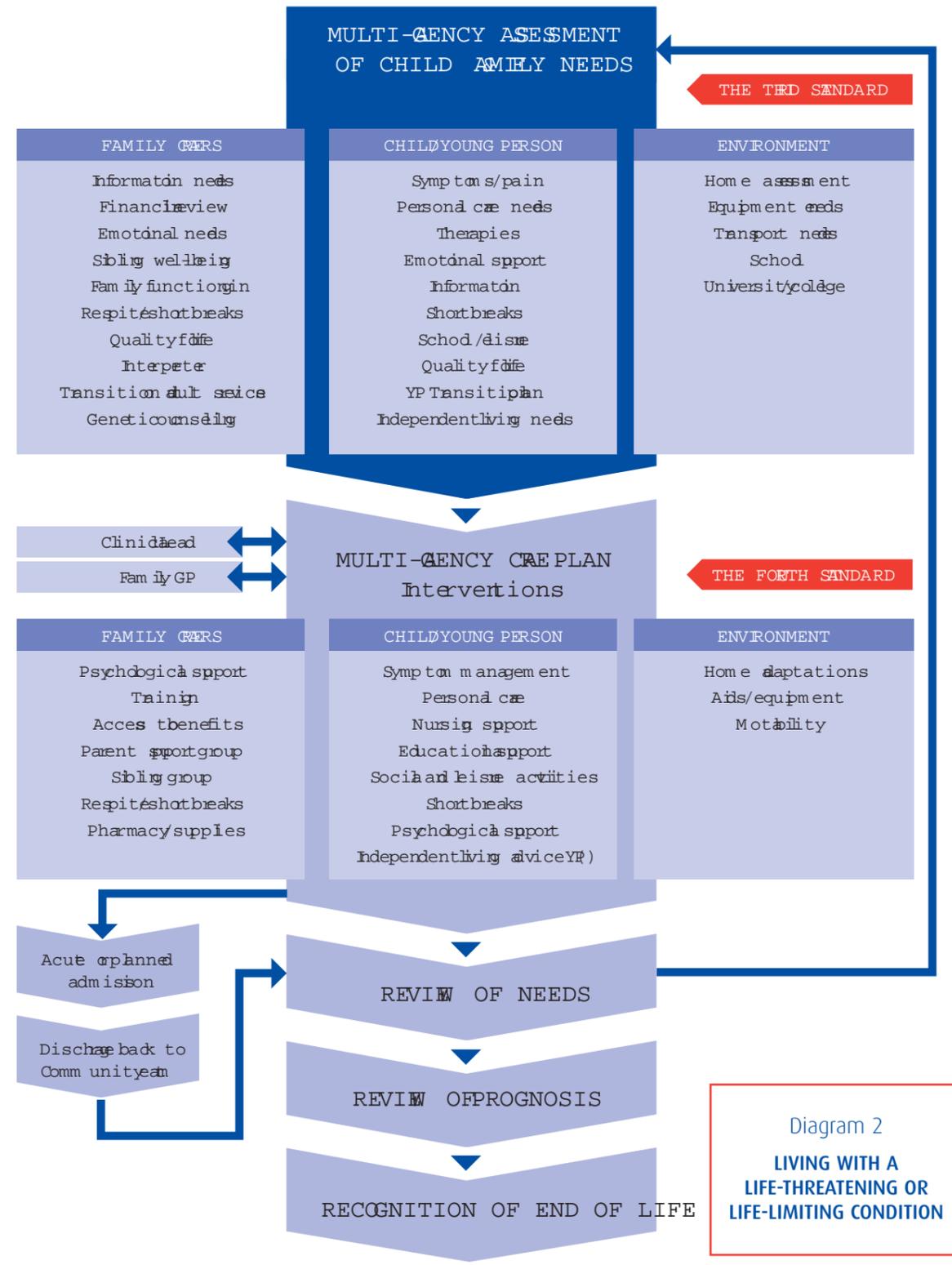


Diagram 2
LIVING WITH A LIFE-THREATENING OR LIFE-LIMITING CONDITION

(continues on page 3)

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The needs assessment will provide the opportunity for the child and family's concerns to be heard and for their full range of needs to be explored. It should empower the family and ensure that they can take control of their lives. Its ultimate goal should be that the child and family receive the help and support they need, when they need it and in the place that they are most comfortable. It should draw together multi-disciplinary expertise to ensure that families are spared repeated individual assessments by different professionals (NSF 2004). Information gathered at the assessment stage should therefore be shared as appropriate and this may be inter-professional and inter-agency. The family should always be consulted before information about them is shared.

One agency to take lead role. In approaching the multi-agency needs assessment it is important to be clear about who is taking lead responsibility for co-ordinating all aspects of the comprehensive care package. This will most often be the community children's nursing team or multi-disciplinary community team. The role of this team will be of vital importance to the family and the assessment will provide the opportunity for the child and family to be registered on the team's palliative care database.

Multi-agency needs assessment. This should be carried out by staff with the appropriate competency and local knowledge, and there should be clear objectives to:

- Gather factual information on the child and family members
- Explore the concerns and feelings of the child and family members, including extended family where possible
- Assess the full range of medical, nursing, practical, social, educational, psychological and spiritual needs
- Reach understanding of the individual situation and the impact on the child and family
- Explore options within local provision
- Culminate in an agreed plan for action and/or interventions

The assessment should cover the needs of the whole family including fathers, siblings, grandparents and significant others identified by the child or young person. The information to be gathered will include factual details on the child and family, details of the professionals and services involved with the family, medical information, the functional abilities of the child, nursing and personal care needs,

emotional needs, educational needs and the family's home circumstances. Assessment should be seen as an ongoing process rather than a single event and, according to the individual family, may take days or even weeks. Information should be recorded systematically and stored securely.

The aim of the assessment is to examine all the individual factors that impact on the child and family's quality of life and guide the delivery of specific services to meet the needs of the family. In Diagram 2, the needs have been set down in three sections: the needs of the child or young person in the central column, the needs of family and carers down the left side, and factors concerning the family's environment down the right side.

For many families the management of the child's symptoms may be the prime consideration. They need to be assured that their child will be as pain and symptom free as possible and will require ongoing support and assistance in achieving this. For children whose symptoms are stable other issues may be of greater importance. Most children will want to enjoy some kind of 'normality' with their peers, so school and leisure opportunities are an essential part of the assessment process.

In providing the best care and attention to their child, many families find little time either for themselves or for their other children. The needs of all family members should receive careful consideration particularly their emotional needs and the need for short breaks, either with or without the ill child. Siblings are often marginalized and may suffer long-term problems at school, among their peers or in their emotional well-being. Some services provide sibling groups that have proved beneficial. The practical needs of the family will also require assessment. The home may need adaptations to accommodate such items as wheelchairs, bath hoists, or other large apparatus. The child's school may need support to enable the child to return and teachers may be willing to be trained in some aspects of the child's care.

The needs of young people are different from those of children and should be considered accordingly. Their emotional needs are likely to be more acute and they will have additional problems such as body image, sexual needs, a need for independence and life goals. For more detail on the needs of young people see the joint Report on Palliative Care for Young People aged 13-24 (ACT/NCHSPCS/SPACC 2001).

Key goals in assessment

- Children and families should have their needs assessed as soon as possible after diagnosis or recognition
- A holistic and multi-agency approach should be used to avoid the need for multiple assessments
- Assessment of needs should be in partnership with the family
- The child or young person should be kept in focus and involved in the process
- Care should be taken to include the needs of fathers and siblings
- Individuality and ethnicity should be respected
- Information should be gathered and recorded systematically to ensure consistency
- Straightforward, non-jargon language should be used
- The issues of confidentiality and consent should be addressed
- Assessment information gathered should be available to the family
- There should be clarity in respect of the lead role
- Those undertaking needs assessments should have appropriate skills and local knowledge

2.2.2 Multi-Agency Care Plan: THE FOURTH STANDARD

Every child and family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A keyworker to assist with this should be identified and agreed with the family.

Following assessment of needs it should be possible to agree with the family the level of support they require and the services that should be involved. Some families' service needs may be minimal in the early stage while for others it may be necessary to call on a wide variety of different services and professionals. There will also be changing needs with peaks and troughs in the number of professionals involved. **The care plan should be a working document** that is shared, providing details of all the professionals and services required for the specific needs identified in the assessment process.

The most important need will be for access to the various services and professionals to be organised and co-ordinated for the family. They also need full information about services and the reassurance that their needs are understood by those with whom they come into contact.

'Information about service providers is very fragmented. We do all our own research and chasing up to get anywhere. The whole situation is a quagmire.'

'I do not know what I am entitled to or who I am supposed to get in touch with.'
(Parents in Voices for Change: ACT 2003)

Provision of a Key Worker. The ideal solution is for each family to have a keyworker to be the main contact through whom they can communicate and who will ensure that their care plan is being delivered effectively (ACT 2003). This would be a person that the family would get to know well and who would have local knowledge and expertise. This desire for a key person has been identified in a number of papers in the past (Proctor et al 1999; Mukherjee et al 1999). In some places this is already working well, often with community children's nurses or the children's social worker in the team taking this role.

'When things are organised and happen right, it's wonderful and we feel the whole system somehow works.'
(Voices for Change, ACT 2003)

Information Support. Information is a vital part of the family's needs. It is inevitable that families will have access to information via the internet, from contact with other families, through the professionals that they meet and from books and other literature. A key skill for the team will be helping families to understand the information they receive and to sift and prioritise it. Each team should have access to interpreters. The child and siblings should also have information according to their age and understanding.

Holistic Approach to the Care Plan. The care plan should be comprehensive, including all aspects of the family's needs. There will be a focus on the child's quality of life including symptom control and personal care, the child's right to education and their emotional and psychological care. In addition the plan should include support to access benefits,

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equipment, aids and adaptations, and flexible short break care. The health of carers and siblings should also be protected.

Some important issues that may not normally be included within a care plan but are vital to comprehensive care are discussed below.

Access to benefits: The financial cost of illness and disability is significant. A child with a severe disability is estimated to cost three times more to support than a child without a disability (Dobson & Middleton 1998). Many families lose one income to facilitate caring and the lack of appropriate childcare can prevent families from finding alternative paid work. It is important that the family has information and support to assist in accessing benefits. Not all benefits are means tested and all families have the right to apply. Complex and rare conditions often require considerable supporting evidence from health professionals to convince benefit agencies.

Access to flexible short break care: The cost to families of caring for a child with complex needs can be social isolation, stress, lack of privacy, exhaustion and strain on relationships. (Glendinning & Kirk 2000; Dobson & Middleton 1998). Short break care can provide time for children and their parents to rest and spend time together or have space from each other. Services provided by the voluntary or statutory sector for short breaks away from the home could be incorporated within the plan. Additionally provision could be made for care within the home to allow families to have a break from their caring responsibilities.

Access to education: All children have a statutory right to education and this includes children with health conditions. Enabling school attendance for some will require support staff and highly complex planning while for others, physical needs may not be a difficulty. Community Children's Nurses can provide a vital link for this group of children. Direct contact between the child's lead teacher or SENCO and the community health team has been identified as particularly useful. (Sloper 2001; Lightfoot 2003) Connexions advisers for young people over 13 can also offer valuable assistance.

Protection of carers' health: With improvements in health treatments and techniques, life expectancy for many conditions has improved dramatically. Many more children are living longer and the number of children reaching their

teens has increased greatly (ACT 2001). This has the result that some families are caring for many years, and long-term stress and exhaustion can seriously affect the health of carers. Lifting and transporting older children also takes its toll as carers get older. Primary care services and the multi-disciplinary community team should work together to ensure that carers' health is considered. This should include psychological support and the care of siblings. Under the Carers and Disabled Children Act 2000, carers can request an assessment of their own needs and may be provided with vouchers to purchase services.

Access to aids and equipment: Many families find that obtaining equipment or aids for their children is fraught with difficulties, with agencies seeming unwilling to co-operate.

'I seem to be constantly reminded about people's budgets. I only want what's best for my son. After his death I would like to remember good times not all the time and effort I spent trying to get care for him.'
(Voices for Change, ACT 2003)

It is essential that families' needs for aids, equipment and adaptations are met in a timely manner. Teams should make every effort to advocate on behalf of their families and assist with forms and meetings with the appropriate agencies.

Planning for transition to adult services: With the increase in the number of children living to their late teens, early twenties or beyond, the need to progress to adult services has become an additional factor in children's palliative care. Because many of the conditions are exclusive to children there may be little medical expertise available in the adult health services. This factor makes both families and professionals reluctant to move young people particularly at a time when they may be deteriorating. However, it is important to begin planning for this transition at an early stage, ideally at around 14. Young people and their families need a considerable amount of time to prepare emotionally and for introductions to new professionals and settings that are often seen as less personal.

It is important that children and young people are involved in decisions affecting their care (Children Act 1989; Children (Scotland) Act 1995; Children's (Northern Ireland) Order 1995). In all countries of the UK young people of 16 and over may legally give consent to or refuse treatment. Children

under 16 may also give or refuse consent if they are deemed to be "competent". Young people approaching the time for moving to adult services require a separate planning process to be initiated well in advance. (For further guidance see Joint Report on Palliative Care for Young People Aged 13-24 Years, ACT/NCHSPCS/SPAPCC 2001).

Key goals for the Multi-agency Care Plan

- Every family should have a key worker to co-ordinate the plan
- Information should be available for the child and family
- The plan should include the whole family and take account of:
 - Child's symptoms and personal care
 - Psychological care for child, siblings and parents
 - Access to benefits and financial assistance
 - Access to flexible short breaks
 - Access to education
 - Protection of carers' health
 - Access to aids and equipment
 - Transition to adult services

Throughout the 'maintenance' phase the child's condition and the needs of the family will fluctuate. There are likely to be periods when there is relative stability but there are also likely to be events or developments when a greater level of active support and intervention is required. This could be an acute episode in the child's health or a planned intervention such as a gastrostomy. These events may affect the family's ability to cope and there will be a period of adjustment to the new situation. The loss of what was their 'normality' and acceptance of the new and sometimes painful reality of changes in their child can be an emotional struggle. In many families the need to review may relate to issues other than the health of the child. Services need to be able to provide sensitive, timely and appropriate support at times of change and instability, to enable families to re-establish control.

Regular review of child and family. To ensure that appropriate support is being provided, it will be necessary to review the family's needs at regular intervals. The stability of the child may dictate the frequency of such reviews or there may be other factors impacting on the family's ability to cope. Families have different thresholds for managing other complex issues such as redundancy, marital breakdown or

family illness, and those professionals working closest with the family will need to be sensitive to their current needs. Some families may need reviews only every 6 months, while others may need them much more often. It should also be possible for a family to request a review at any time.

The assessment process will be carried out in the same way as before, using the documented details of the child and family against which to highlight changes and therefore differing needs. The possibility that a review may be needed after a hospital admission should be acknowledged and in this case liaison between hospital and community staff on transfer home will again be vital. This could also be a time when the child's prognosis could have changed and care should be taken to consider the child's future and discuss the prognosis with the family. An alteration in prognosis may mean that the family makes different decisions and considers end of life scenarios. After each review, changes should be documented and incorporated into the revised care plan.

Regular multi-disciplinary/ multi-agency review meetings are also essential to ensure that co-ordination continues effectively and that services and professionals are delivering the agreed care plan. The family's view of the delivery of their services will be a crucial part of this review.

Key goals in reviewing needs

- The child and family's needs should be regularly reviewed
- The family should be able to request a review at any time
- Services and professionals should regularly review their effectiveness in co-ordinating and delivering care plans
- Families will need extra support at key times, particularly following hospital admission, a change in the child's condition or in times of family crisis
- A change in prognosis should be communicated to the family
- A new care plan should be agreed to take account of changes

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2.3 Care Pathway 3: End of Life and Bereavement

2.3.1 Recognition of end of life

Predicting the time when a child is likely to move into the terminal phase is not easy. For some, there may have been a series of peaks and troughs in the child's condition and it is not uncommon for children to return to greater stability following a period of serious decline. The realisation that death is imminent may be quite sudden, possibly only hours or days before death. The families of these children may have had little time to acknowledge this reality or plan for the death. For others, however, movement into the end of life phase is clearer when there has been a decision to stop all life-prolonging treatment. The family will be aware that the child's death is inevitable and will have some time to plan. They are likely to be anxious for reassurance that pain and symptoms will be adequately controlled and that their child will not suffer.

Professionals working with these children and families should be honest and open about the probability that the child's life is nearing an end. Families should not be given false hope and should be allowed to plan for death. The term 'good death' is difficult to define, as it is personal to each individual. But the key is that the child and family should be able to exercise choice and receive full care and support in that choice. It is therefore advisable for a plan to be agreed in advance, based on the family's needs and wishes. Making a plan can help to mitigate some of the child and family's anxieties and ensure that events happen as they want (Diagram 3).

In some places pathways for the care of the dying have already been devised. The Liverpool Integrated Care Pathway for the Dying Patient (Ellershaw and Wilkinson 2003) is an example of a multi-professional document that incorporates evidence-based practice and appropriate guidelines. It deals with management of physical problems and guides professionals through the care of the patient and family immediately following death. The pathway replaces all other documentation in this phase of care. The Liverpool Pathway is now being modified for use with children (Brook and Williams 2003).

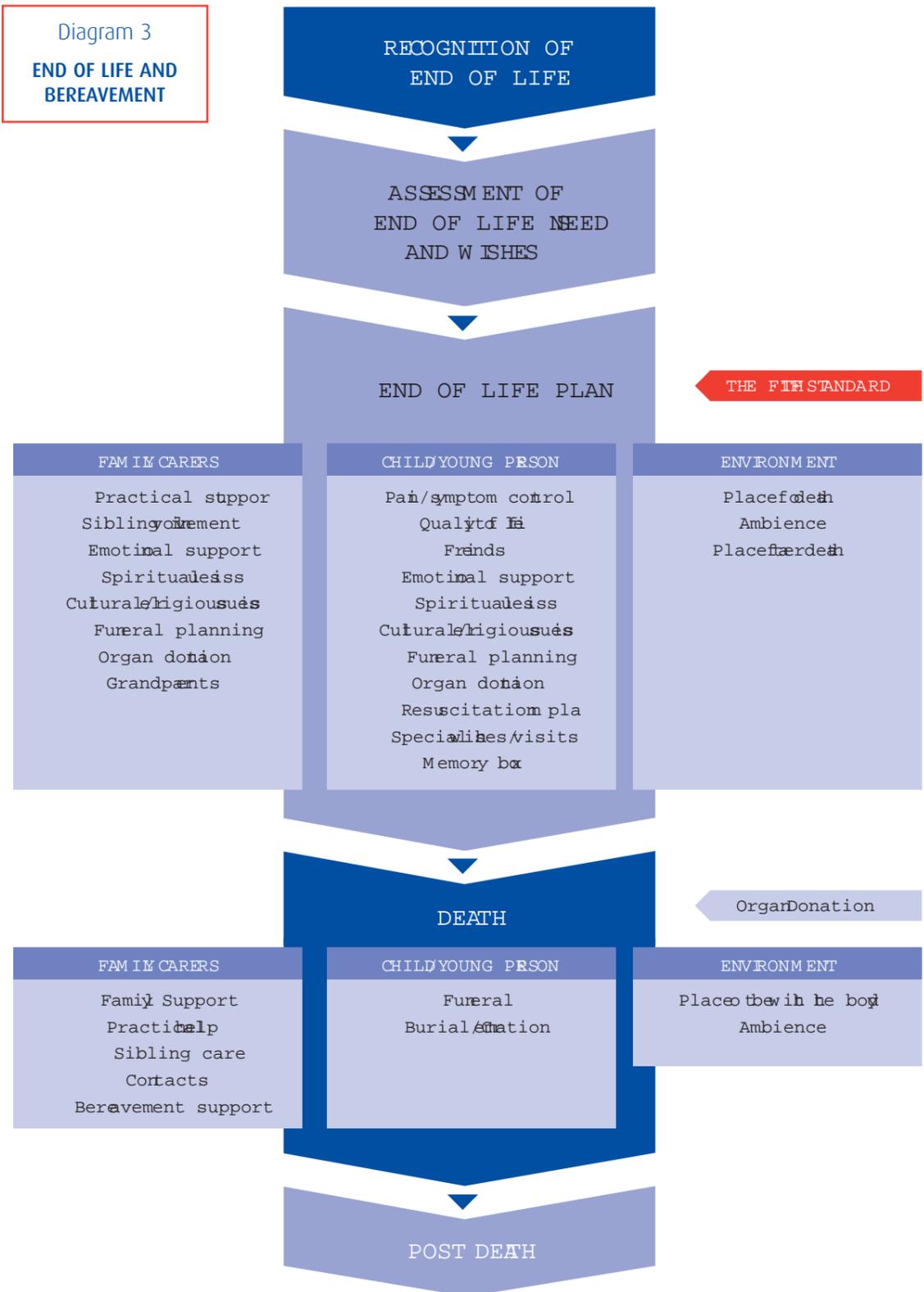
2.3.2 End of life plan: THE FIFTH STANDARD

Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible

Planning end of life care with the family. As soon as it becomes apparent that the child is approaching the end of life it is important that all professionals and agencies involved are brought together with the family to discuss their needs and wishes. This could be a few weeks after the terminal phase has been recognised or it may need to be done urgently if the child is deteriorating rapidly. This is likely to be a very difficult time for the family and it may be the point at which they are facing up to the reality of their child's death for the first time. Some people who have been involved with the family may no longer be needed and a small core team may need to be identified. Professionals sometimes find it difficult to 'let go' of the child or family and may themselves need support to recognise that families need to have as much privacy as possible and that time with their child is very precious.

The child's quality of life up to the point of death will be a major consideration and there may be difficult decisions surrounding the withdrawal of non-essential drugs or other invasive interventions. The Royal College of Paediatrics and Child Health has published guidance on withdrawing treatment in children (RCPCH 1997) and the British Medical Association has also published guidance and extensive discussion of the ethics around end of life care (BMA 1999).

The suggestion may be made that the child should not be resuscitated and precise details about what the family want and do not want should be explored. It may be possible to develop a written Personal Resuscitation Plan with the consultant and other people looking after the child, to assist in communication between different professionals. The family may also wish to discuss the options with regard to organ donation and the subject of post mortem may need to be explained. Parents should be fully informed about these issues and should feel that their decisions are understood and respected by all concerned. Young people with the capacity to decide independently should be involved in making decisions about end of life choices.



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The environment in which the family feels most comfortable will also be a consideration. Many wish to be at home but others may choose a children's hospice or a hospital where they feel more confident to deal with emergencies. A combination of these places is also possible and this will require efficient collaborative working. Whatever the choice, the family will need 24-hour access to care in the terminal stage. Clarification will be needed about who will be prescribing and that they have the appropriate skills and knowledge or, if not, will be supported by a physician who has. Planning will be required for supplies of medication and provision of out of hours pharmacy needs.

Plan for providing terminal care: The child or young person must receive effective pain and symptom control. The key will be ensuring that regular symptom reviews are undertaken and the right treatment administered. The appropriate analgesia should be administered at regular dosing intervals with adjunctive drug therapy for symptom and side-effect control. There is a range of pain assessment tools appropriate to the age and understanding of individual infants, children and adolescents, in particular those produced by the Royal College of Nursing. It may sometimes be necessary to request advice and this is far preferable to getting something wrong and jeopardising the family's trust. The family's decision to provide terminal care at home may be thwarted if there is a breakdown in symptom control resulting in admission to hospital.

There will also be the possibility of other distressing symptoms and the child and family will need reassurance that these can be managed effectively. It is important that the family and the team have 24-hour access to a paediatric palliative care specialist, paediatrician or specially trained GP so that symptoms and pain can be controlled outside normal working hours and unnecessary emergency admissions to hospital can be avoided.

Complementary therapies such as music therapy, play therapy, story-telling, visualisation or relaxation techniques, and even hypnosis may have a role to play and should be considered as part of the care if the family wish.

The agreed end of life care plan will need to be documented, including the personalised resuscitation plan setting out what emergency treatment is to be used and what is not to be used by ambulance crews and local accident and emergency

departments. It may be helpful to discuss this with the local emergency services and provide them with a copy of the document. The plan should allow for ongoing review of care and changing goals to comply with the wishes of the family. It is essential that all in the team are informed of changes and kept up to date with the child's care.

Supporting the child and family's choices for quality of life:

Parents and other significant family members should be encouraged and supported to continue their caring role with the child or young person. Depending on the age of the child the school community may continue to be involved and informed. The child may wish to continue with school work and this should be facilitated. He or she may want to continue seeing friends, and carry on with other pleasurable activities for as long as possible. Siblings and grandparents, where appropriate, should be included in discussions about choices on quality of life.

Emotional support is essential at this time. Some families find the thought of discussing death with the child or young person extremely distressing and may feel it is better to shield the child from such knowledge. In all but the very youngest it is most likely that the child already knows that death is possible but feels responsible for the distress this will cause the family. Planning together for death may provide a positive experience for both the child and the family at an otherwise totally bleak time. There may be special wishes or goals to achieve, the child may want to express their wishes about the funeral or their belongings after death, they may want to provide a memory box for friends or family or they may have views about spiritual issues that they want to share. It is important that there is someone on the team, or known to the team, with the skill and compassion to support the family in approaching the discussion of death, and opening the possibility for the child or young person to make their own plans.

Key Goals in Planning for End of Life Care

- Professionals should be open and honest with families when the approach to end of life is recognised
- Joint planning with families and relevant professionals should take place as soon as possible
- A written plan of care should be agreed including decisions about methods of resuscitation; emergency services should be informed
- Care plans should be reviewed and altered to take account of changes
- There should be 24-hours access to pain and symptom control including access to medication
- Those managing the control of symptoms should be suitably qualified and experienced
- Emotional and spiritual support should be available to the child and carers
- Children and families should be supported in their choices and goals for quality of life to the end

2.3.3 At the time of death

This will be an extremely painful time for the family and also for those who are supporting them. The child will need to have loved ones close by, with the necessary privacy and space. Professionals should be sensitive to these needs and should not obstruct the family's own 'processes'. In some cases withdrawal of life prolonging treatment such as mechanical ventilation may be suggested. The family may need time to come to terms with the plan. Occasionally there may be conflict between the family and professionals as to what is in the best interests of the child (RCPCH 1997). With patience and sensitivity, allowing the family as much time as possible, agreement to withdraw inappropriate treatment can be achieved. In some cases the family may decide they wish to transfer to another setting, such as a children's hospice, and this should be supported wherever possible.

There will be a need at this time for the family to consider what they want after the child's death. Where would they prefer the child to go; who will need to be contacted; who will deal with the death certificate; is there to be a post mortem; has organ donation been discussed? If the family wishes to take the child home after death in hospital this should be recorded in the child's notes.

2.3.4 After death

After the death it is vital that parents retain control and choice in the care of their child's body. Families need to have time and privacy with their child in the hours and days following the death. They need to know that almost anything they decide is possible, including moving the body to another place. Parents will appreciate advice from the care team or funeral director about care of the body at home (Dominica, 1997). In children's hospices a special 'cold room' will be available to the family for as long as they wish. It may also be possible to arrange for a mobile cooling device in the family home so that the child's body can remain at home for a period. The family may wish to take photographs, a lock of hair or hand or footprints.

Care should be taken to ensure that the family's religious or cultural beliefs and rituals are respected. Parents should be consulted about whether they want to be involved in laying out the child and choosing the clothes to be worn. They will need reassurance that their child will be treated with dignity and respect by any professional handling the body.

Siblings should be given opportunities to express their emotions openly and ask questions. Their needs can often be overlooked by busy professionals, or parents overcome with grief. They should be consulted about whether they wish to see their brother or sister's body and should not be excluded from decisions about funeral arrangements. They may decide they wish to make a special contribution such as a prayer or a poem. They may also wish to place a gift or memento in their sibling's coffin. Grandparents also need sensitive consideration as they are likely to be grieving not only for their grandchild but also for their own child's sake.

There will be an immediate need to inform all those in contact with the family that the child has died. The family's key worker or another member of the team can assist in this if the family wishes. People to contact may include the GP, community or specialist nurses, health visitor, social worker, school, short break service, transport service, children's hospice and ambulance service. It is also important to ensure that any department or service expecting the child at an appointment is informed to ensure that 'did not attend' letters are not sent out. Where appropriate, benefit agencies should be informed as soon as possible.

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Written information should be provided for the family about procedures and entitlements following the death, to include:

- Registering the death
- Procedure required for cremation
- Contact details of funeral director
- Advice on benefits or entitlements

In the event of a death on a general ward, staff may not always be clear about procedures. Training and simple written resources should be available to all staff, particularly where paediatric trained staff may not be available 24 hours a day.

When a death is expected it is usually not necessary to hold a post mortem. Some families may be asked if they will elect for post mortem examination to assist the furtherance of knowledge about rare childhood conditions. The family should not feel they are under any pressure or compulsion to agree to this and must be provided with full information about post mortem procedures. The consent of the family to their child's post mortem examination must be based on truth and understanding and they must be reassured that nothing will be happening that they have not agreed to. In very rare cases, such as sudden unexpected death or death after surgery, a post mortem may be required by the coroner and the family should receive the same full information about the procedures involved.

2.4 Continuing Bereavement Support

The death of the child is not the end of the pathway for the family. They will be grieving their loss for many months and years to come and many will need some support in this. The body of literature on bereavement is extremely large and within it much has been written about the grieving process. In the past some emphasis has been placed on concepts like 'stages or tasks of grieving' (Kubler-Ross 1970) but these may not always reflect the experiences or particular needs of bereaved families (Davies 2004). More recent perspectives on parental grief such as 'continuing bonds' recognise that parents wish to continue 'holding on' to their relationship with their child rather than 'letting go' (Silverman and Klass 1996). It should be acknowledged that grief for a beloved

child may never end or resolve, as Talbot (2002), a bereaved mother and grief counsellor, notes:

'Healing after the death of a child does not mean becoming totally pain-free. Healing means integrating and learning how to live with loss. It means being able to love others and reinvest in life again. Healing comes when parents decide that they will not permit pain to be the only expression of their continuing love for their child.'

Those who have been involved with the family throughout are probably best placed to offer support. Only in rare cases will the needs be extreme requiring specialist intervention. Terminal care that is appropriate and sensitive to the family's own needs can provide support in bereavement.

The family should feel they are able to ask for help if they need it. Those in the team who are working with the family should make frequent follow up contact to ensure that the family's needs are met. It can be helpful if difficult times such as birthdays, Christmas or the anniversary of the child's death are remembered. Particular care is needed with siblings. Brothers and sisters have been referred to as the 'forgotten mourners' because they may not have expressed their needs directly (Hindmarsh 2000). Siblings are affected not only by the loss of their brother or sister but by the impact this has on the family and the relationships within it. Children should be included and not shielded from the grief felt by others in the family, so that they do not feel that they also have to hide their feelings. Attendance at funerals and taking part in other family events and rituals with appropriate information and support is likely to be helpful. [e.g. Candle Project].

The family may also experience secondary losses. The nature of their relationships with professionals will change. The intensive involvement, the friendship and support of members of the team will largely cease and many families feel suddenly cut off from what was previously the major part of their lives. In addition they may suffer financial hardship as allowances are likely to be withdrawn or reduced. The family GP and primary care team should provide as much support as possible and should demonstrate understanding that for several years members of the family may present with emotional or physical problems that need time and care.

Professionals who have been closely involved with the care of the child and family will also need emotional and psychological support.

Key Goals in Care After Death

- The family should be allowed time and privacy with their child
- Parents should feel in control of events after death and should be able to make their own choices
- Practical advice and written information should be given about removal and care of the body, official procedures and entitlements
- The needs of siblings and grandparents should be considered and included at the time of death and immediately afterwards
- Fully informed consent should be given for post mortem
- Contacts should immediately be informed of the death
- Bereavement support should be offered for as long as the family needs
- The bereavement needs of siblings should be recognised and support provided
- The needs of care staff should be considered

Part 3 | Appendices

Appendix I: Definitions

National Standards

National standards are authoritative statements based on research evidence or consensus of experts. They may be set by the Department of Health (DH), the Department for Education and Skills (DfES), Social Services Inspectorate (SSI), or others. They aim to set down important benchmarks for maintaining equitable services for people in all areas of the country.

Protocol Based Care

Protocols are detailed statements about how care is delivered. They are driven by evidence of clinical- and cost-effectiveness and can be used for improving safety, quality and consistency of service provision and for co-ordinating services across a range of environments and professions.

Local protocols are designed to operate at a local level to implement National Standards/National Protocols and to guide best practice. They can relate to health, social services, education or all three of these. Protocols are developed to reflect local services and staffing arrangements and to integrate the services provided by different disciplines or organisations.

Appendix II: ACT Charter

1. Every child shall be treated with dignity and respect whatever their physical or intellectual ability
2. Parents shall be acknowledged as the primary carers and involved as partners in all care and decisions involving their child
3. Every child shall be given the opportunity to participate in decisions affecting his or her care, according to age and understanding
4. An honest and open approach shall be the basis of all communication
5. Information shall be provided for the parent, the child, the siblings and other relatives, appropriate to age and understanding
6. The family home shall remain the centre of caring whenever possible. Care away from home shall be provided in a child-centred environment by staff trained in the care of children

7. Every family shall have access to a 24-hour multi-disciplinary children's palliative care team for flexible support in the home, and be in the care of a local paediatrician
8. Every child and family shall receive emotional, psychological and spiritual support to meet their needs. This shall begin at diagnosis and continue throughout the child's lifetime, death and in bereavement
9. Every family shall be entitled to a named keyworker who will enable the family to build up and maintain access to an appropriate network of support
10. Every family shall be given the opportunity of a consultation with a paediatric specialist who has particular knowledge of the child's condition
11. Every family shall have access to flexible short term breaks (respite care) both in their own home and away from home, with appropriate children's nursing and medical support
12. Every child shall have access to education and other appropriate childhood activities
13. The needs of adolescents and young people shall be addressed and planned for well in advance
14. Every family shall have timely access to practical support, including clinical equipment, financial grants, suitable housing and domestic help
(ACT 4th Edition 2004)

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