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Please respond with comments by Wednesday 18th August 2010 to Chris Robinson at SWIA [chris.robinson@swia.gsi.gov.uk](mailto:chris.robinson@swia.gsi.gov.uk).



Children's Hospice Association Scotland  
Sharing the Caring

Draft Guide

**A guide for end of life planning for children and young people**

**Draft for consultation  
Comments by 18/08/2010**

5.7.2010

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This guide has come from a working partnership between CHAS (Children's Hospice Association Scotland)<sup>1</sup>, SWIA (Social Work Inspection Agency)<sup>2</sup> and staff from Highland Council and Scottish Borders Council. Parents, young people and carers have been our partners and their views and words are central to this guide.

### **Note for comments**

In your comments please be as detailed and critical as you can – these will be welcome and we will take them into account in the final version.

If you would like to discuss the guide please email or telephone:

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Please send all comments to Chris Robinson by 2<sup>nd</sup> August 2010.

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<sup>1</sup> CHAS is a Scottish charity that provides the only hospice services in Scotland for children and young people with life-limiting conditions. A children's hospice offers professional care, practical help and emotional support to the whole family usually from the day of acceptance, to the death of their child, and beyond. We discuss the aims and role of children's hospice later in this guide.

<sup>2</sup> The Social Work Inspection Agency is an independent agency of the Scottish Government which reviews and reports on the performance of each council's social work services; the agency has other responsibilities including reviewing the deaths of all 'looked after children' on behalf of Scottish Ministers.

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Forwards by Chief Executives of CHAS and SWIA  
And parent (s) to follow

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- 9. Support after death for families and some practical suggestions**
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***'Life is either a daring adventure or nothing at all'.***

A young person used these words to describe the life of her sister who died at the age 17 having lived a full and exciting life.

## **1. Introduction**

This guide is for people who care professionally for children and young people with life limiting conditions. The guide is based on what families and carers have told us is important for people working with their child.<sup>3</sup>

'It is not a how to do it guide' - there is no blue print to follow for the complex practical and emotional journey that the child, their families and carers take which affects each person differently.

***'Sometimes, being the very, very best parent does not mean fighting to cure, but fighting to do the best you can for your child's quality of life.'***

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Children and young people with life limiting conditions live their lives in many places and with different people. Not all can live with their families and some are

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<sup>3</sup> We recognise that many different people care for children and these include families, brothers and sisters grandparents, friends, foster carers, short break carers, professionals in health, social work and social care and education. To avoid cumbersome repetition we refer to families and carers except where it is relevant to identify a particular group.

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“looked after”, and “looked after and accommodated”.<sup>4</sup> All children and young people have different needs depending on their age and stage, personality, medical condition and family circumstances. Children and young people may have complex needs and they may not follow what is thought of as the usual stages of development. In this guide we respect these differences and discuss them when appropriate within the context of themes which may be relevant to all children whose life is limited.

## **2. The news that a child has a life limiting condition**

### ***‘I feel left out like I’m in a bubble’***

Child’s drawing and this quote to come in here

Some parents know from the birth of their child that she or he may not live for long or will not live into adult life. For others this knowledge may come suddenly through being told by a health professional or slowly through a dawning recognition. However the realisation comes, it is a profound moment for every family and their child.

*‘I didn’t hear what they (the doctors) told us, I wanted it to be a mistake.’*

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<sup>4</sup> These are legal terms for children who are cared for by councils either with the consent of their parent(s) or through the Children’s Hearing. Some councils require children who need short breaks/ respite care to become voluntarily ‘looked after’ whilst others do not.

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*'It's scary when you hear about a child dying... you realise how fragile your own child's life is...'*

For many children there are complex issues around diagnosis and the family and carers will receive and process information in different ways. Some families have told us of consultants who have come to their homes to discuss their child's diagnosis; for others it was a short conversation in an outpatient clinic with limited follow up.

*'I was sure something could be done, an operation, something, it took a long time to realise there was nothing. My family kept asking ...they thought if we did more to push the hospital something could be done. Like we were failing her.'*

Other family members, carers and professionals will recognise that each reaction will be individual and even people with close relationships e.g. parents who are in a secure and loving relationship with each other may react very differently and find it hard to communicate. However, because the issues are so sensitive, professionals may need to be aware of the risk of avoiding the topic altogether. A children's hospice can create a safe place, which can be important in helping to open communication with and between family members.

The child or young person, if they are of age and stage to comprehend their diagnosis, will have distinct and separate needs from their family and or carers.

***'I might look ok on the outside but inside it might be different.'***

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Child's drawing and this quote to come in here

Children who are looked after away from home will have an added complexity to their comprehension of their condition. They may wonder *'is this why I cannot live at home.'* They may have fresh hopes and fears. *'Now they know I am so ill perhaps I can go back home, will it be different now?'* Their birth family and their carers may have differences in understanding their condition and in approaches to palliative care.

There are tremendous challenges to social workers working with the looked after child or young person, their carers and their extended or birth family. Good communication and planning are crucial and we discuss these later.

Many social workers have little experience or training in working with a child who has a life limiting condition and sources of support and information can be found by contacting a children's hospice and other organisations. (Appendix 2)

### **3. Where can help and support come from?**

*'We had to wait 18 months for access to specialist equipment and an occupational therapist. It's always a battle.'* (A parent)

*'I cancelled my first visit (to the children's hospice) I couldn't accept that Katie needed a hospice. The first thing you think is that your child is dying, why else would you go to a hospice. I know now that it's not all about death. It is a happy place. as soon as we walked through the door we were made to feel so welcome.'* (A parent)

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*'All too often in the past children and very particularly young people have been required to accept health care based on models of service and facilities designed primarily for the adult population.'* (Delivering a Healthy Future (2007) Scottish Executive)

Many families and children and young people will look to carers and professionals for both practical and emotional support.

Services and support are very often offered by a team. *Getting it right for every child*<sup>5</sup> recognises the importance of the 'team around the child' which brings together all who are concerned to provide care and support. A lead professional or key worker who is known to and identified by the child and family is vital to making sure communication is effective and services co-ordinated. Parents who contributed to the preparation of this guide told us about duplication of effort, poor communication between agencies and having to contact several different people to get an answer to a problem.

*'One of the worst things was having to explain over and over again our child's condition and what it meant for her... We know it was a rare condition but ...'*

*'I'm a single parent- I wondered if the health people and the social workers ever spoke to each other.'*

When young people reach the stage of moving to adult services these issues can become worse for many families and carers and we discuss transitions in a later section of this guide.

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The sources of specialist services for many children in Scotland more especially outwith the central belt are sparse. Many professionals may have limited or no previous experience of palliative care of children and young people and ready sources of help and advice are important. Some councils and health boards have developed specialist resource packs which can be available at short notice to professionals. In Fife and the Scottish Borders, groups are working to prepare these packs which should enable professionals to be able to find appropriate contacts and therefore resources for children and young people as well as their families.

#### **4. The work of the hospice movement in Scotland**

Rachel House and Robin House exist to provide specialist short planned breaks for families with a child or young person who is not expected to live into adulthood as well as to provide end of life and bereavement care when these are needed. At all times the hospice team will maintain a clear focus on the individual needs of the sick child, brothers and sisters, parents and other significant family members.

In particular Rachel House and Robin House will:

- Promote a happy and caring environment.
- Ensure the individual preferences of children and families in respect of treatment and intervention are both identified and respected.
- Ensure children and families are central in decision making.
- Use a multi disciplinary approach, recognising the physical, emotional,

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- spiritual and social needs of each child and family unit.
- Offer 24 hour support to children and families using them, at the hospice, by telephone, or in the family home.
- Offer support to the child and family in the time leading up to death and bereavement support thereafter.
- Provide for the individual spiritual and emotional needs of children and families by facilitating contact with local religious leaders, but always recognising individual differences and needs.
- Work closely with other agencies involved in child and family care, promoting the philosophy of Rachel House and Robin House.
- Support staff and volunteers by providing access to continuing education and training and recognising individual needs.

## 5. Parents and sibling groups

*'Empathy from other mums in a similar situation is what keeps me going, we need each other and give and receive so much understanding due to our unique connection.'*

Parents and carers told us of the help which belonging to a group could give. The opportunity to share experiences with others who had similar issues was valued

A parents group in Highland told us their views on the importance of support.

All of the mothers had children with complex needs and life threatening or limiting conditions. The group began meeting following the unexpected deaths of two of the children who belonged to the same group as their children. Whilst the parents felt very sad for the bereaved families, they also recognised their own

anxieties for their children. There was a sense of collective sadness within the school the children had attended, for students, staff and within the wider community. An informal meeting which involved the hospital chaplain,

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community nurse and social worker sowed the seeds for a ongoing regular group which gives parents the opportunity to share feelings and issues together.

Parents explained that their unique circumstances make it much easier to share thoughts and feelings and discuss issues with people who have similar experiences of bringing up children with complex needs.

### **Sibling groups**

*'Its great being able to go off and do things without feeling guilty about whether my sister will be able to join in or who can look after her.'*

*'It's cool meeting other kids who are the same.'*

The needs of brothers and sisters of children with life limiting conditions are important. Parents or carers have an enormous challenge to make sure that siblings are getting appropriate attention as well as recognising their feelings and concerns for their brother or sister.

In 1998 in Highland region the Birnie Centre Siblings Group was established in response to recognition of the needs of brothers and sisters of children with complex medical conditions. The groups meet monthly during term time and

there are groups for three age groups from 6-8 years, 8-12 years and 12-16 years.

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The group is run by volunteers and funded by charitable donations and affiliation to the Friends of the Birnie Centre. Transport for the children is provided and a wide range of activities are offered. One parent explained:

*'My ten year old son goes to the Siblings Group at the Birnie Centre. He really enjoys his time there. It allows my husband and me to spend time with our daughter. My son really loves the activities and outings as well as the chance to share experiences with others, and not to feel awkward or embarrassed to talk about how he feels. It is a very important part of family support and rewarding for us all.'*

The children's hospices also provide individual activities for sisters and brothers and also for them altogether. These were summed up by one older sister as follows;

*'The weekends we spent together at Rachel House were so enjoyable. The staff would facilitate things for Robert and Anna and me to do together. Anna's designated carer for the day would include Robert and me whenever we wanted it whether it was participating in activities with Anna in or around the house for example, creating things and generally making a mess in the art room, or playing games in the garden. Or helping bath Anna in the special bath which was probably one of the highlights of Anna's weekends at Rachel House.'*

Children's hospices have been key to recognising that fun is important for the child and everyone in the family including brothers and sisters.

Caring for a child or young person with a life-limiting condition can place extreme demands on parents, physically and emotionally, as they often become the primary carers.

A key role of Rachel House and Robin House is to provide short planned breaks which enables the whole family to stay together in a 'home from home'

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environment. The multi-professional team provides complex care alongside play and activities for the ill child. Siblings are able to benefit from inclusion in activities and quality time with their parents, who in turn are able to talk, have time together and benefit from uninterrupted sleep.

The whole family can enjoy prepared meals, and the environment created by staff and volunteers is homely and relaxing. Families meet others in similar situations, and this is invaluable for parents and children alike.

Short planned breaks for a child or young person without their parents are also provided. For some young people, it allows an element of independence and gives parents time to catch up on things at home.

Short planned breaks allow families to plan ahead, and enables CHAS staff and volunteers to build relationships with all family members. This enables effective and ongoing support.

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## 6. Planning

The Girfec<sup>6</sup> (Getting it right for every child) framework and assessment can help professionals in forward planning with children and young people and their carers. Some practitioners have told us that adaptations are needed to meet the requirements of palliative care, the uncertain and complex needs of young

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people with life limiting conditions. Experience of implementing the framework was set out by a senior social worker.

*'Our experience has been that an honest and sensitive assessment using the framework as it is presented can clearly identify the needs of the child or young person and the family. We have found the use of the tools available, unaltered; highlight the often significant gaps between experiences of a well child and one with a life limiting condition. The outcome may appear overwhelming by this approach but it will give a true reflection of the young person's situation and assist in a useful plan for support. Our experience has also shown us that frequent and ongoing assessment and parallel planning is a useful approach to take'.*

Holistic symptom management is central to planning and care of children and young people with palliative care and end of life needs. This is more complicated because many care professionals do not have regular experience of working with children and young people with those needs, and all the different symptoms which are associated with care at these times.

The list of symptoms that children can experience is nearly endless but commonly includes discomfort or pain, breathless and noisy breathing, anxiety, constipation, diarrhoea, nausea, vomiting, acid reflux, dizziness, itch, muscle spasm, cough, skin or oral symptoms and symptoms associated with infection or epilepsy, as well as side effects from medications. On top of this list is the significant chance of symptoms related to psychological and depressive phenomena.

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Parents and carers may also be more easily able to recognise these symptoms than a professional who is meeting the child for the first time. However good outcomes can be achieved by a combination of applying and adapting their professional training, listening to parents and carers and consulting colleagues with more specialised knowledge. Managing symptoms may be achieved through medication but consideration should also be given to other approaches such as non medication therapies, play and relaxation. The children's hospices have highly skilled play therapists.

### **End of life planning**

Planning involving all agencies and the child or young person and their family and carers is crucial for good end of life care. Some staff told us they felt it was insensitive to be discussing plans for end of life care for a child or young person and that they felt uncaring to the child and family. Understandably parents carers and professionals can be very wary of opening up discussion of end of life issues. For parents and often professionals this will be the first time they have to recognise that plans should be made and that the wishes expressed in words will define actions.

Families should have an identified lead professional who is recognised by them and other care professionals as the person who can co-ordinate and communicate everyone's efforts.

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It is helpful to nominate a key worker who knows or can come to know the family well and can be responsible for supporting the family with advocating their wishes and needs throughout this time.

Professionals need to indicate their willingness to discuss difficult issues of a child's death. Sensitive exploration of wishes and fears will often open up a path to ongoing deeper discussions and planning. 'What if ...?' questions should be anticipated and prepared for, especially from children and young people. The more confident and comfortable the worker appears when having these discussions, the more able the family will feel to discuss things when they are ready.

A person centred approach is essential. Families should be at the centre of all decision making. To enable this it is important to give consistent information in a timely manner as families will be experiencing multiple losses throughout this time and will have a need to have as much control over their situation as is possible. Conducting communication at the family's pace is vital. Information needs to be in an accessible format and sufficient to enable the young person and family to make informed decisions,

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Professionals involved with the family should communicate with each other frequently and ensure services are planned and co-ordinated. Professionals

providing specialist palliative care services should be approached as consultants as needed.

Each plan will be unique to each child/ young person but there should be some common factors.

- The plan should be holistic and include things to address hopes, fears, wishes and choices
- The plan may need to be frequently changed and updated to maintain its relevance in response to the changing needs of the child/young person and family

It is important for key staff supporting the family through this time to be included in supporting the family after the death of the child or young person. The key worker will have an important role to play at this time. They should have built up an understanding of each family member's resilience, i.e. awareness of previous losses and coping strategies. This can greatly assist the individual family members to be supported through their grief.

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Professionals should also be aware of other agencies the family can use if needed, e.g. CRUSE, Compassionate Friends, Richmond's Hope, and CHAS. In addition there will be other counselling and therapeutic services available that can be accessed via the family's General Medical Practice.

ACT (The Association for Palliative Care) <sup>7</sup> has a wealth of practical material about end of life planning and creating pathways to ensure that there is emphasis on quality of life and symptom reduction as well planning for the end of life.

The important areas of planning are:

- Wish lists for children and their families. These are valuable and the child or young person and family members can contribute to them.
- Emergency plans: What to do if there is an acute deterioration in a child or young person's condition? Professionals should be involved and responses identified for day or night time emergencies including guidance on when to seek return to hospital, when to stay at home or when it may be appropriate to seek admission to a children's hospice.
- How to provide a 'just in case' box for medications which may be needed and could prevent unnecessary admission to hospital, thus preventing the need for urgent medication orders in an emergency situation.

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- Decision making and recording of family views on when cardiopulmonary resuscitation should be attempted, or not and communicating this decision to other professionals.<sup>8</sup>
- Planning for greater involvement of the Primary Care Health Team at an early stage to reduce unplanned admissions to hospital.

### **Meeting Religious and Cultural Needs**

When meeting families for the first time, it is important to be sensitive to their religious and cultural beliefs. Families and members of families vary in how much or little they practice their faith. There are many variations within faith groups as there are between them and how a family will interpret and practice their faith at time of death of a family member is an individual matter. Always ask a family and never assume you know. There are some resources which may be useful. (Appendix 2)

When SWIA reviewed the end of life care plans of looked after children it found that when there were clear plans which had been shared with key people there were fewer disputes and misunderstandings at crucial times. The legal rights of the young person, carer, and foster carer and where appropriate birth parents need to be clarified when the child or young person becomes looked after and

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<sup>8</sup> The Scottish Government will launch a new DNR in 2010 with a more specific form for children under 16years – further details of this can be included in the final version of the guide.

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not at the end of their life. Social workers and social care workers need to be confident that these are matters which need to be discussed. (Appendix 3 to follow will have a summary of current legislation with respect to looked after children)

Giving staff confidence to explore the issues and to seek help and guidance is an important role for managers, as is helping staff to recognise that skills gained in counselling, working with children and families are transferable. Working with loss and separation is an element of much social work and social care and helping staff to recognise the parallels and strengths of their practice can reduce the barriers to helping a family whose child has a life limiting condition.

There are many aspects to good planning, including the importance of having fun, fulfilling wishes and creating positive memories.

## **7. Creating positive memories and sharing difficult feelings**

It is important that we capture significant events in the lives of children and young people and record their personality and sense of who they are. We need to create opportunities for fun and achievement and for expressing difficult feelings and thoughts. The ages and stages suggested are a general guide as all children are different.

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### **Early stage of development equivalent to birth to 3 years**

Children who have limited language may communicate through sounds and body language and will have the ability to express simple sensations and emotions happy, distressed, hungry, tired etc.

#### **Activities that can capture memories for this age group include:**

Hand and foot prints – these can be done at each stage of the child's growth.

Weight and height are recorded. Locks of hair, photographs of activities enjoyed together can be important mementos of happy days.

#### **Sharing difficult feelings**

Keeping a diary or journal of difficult times can be equally as important as recording the positive times. It will make sense for the child/siblings/parents and other family as a record of their life and history and give a sense of the child and the difficulties they faced.

### **Stage of development which maybe equivalent to 3 to 6 years**

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By this stage the child may be developing a range of words and forming sentences based on an awareness of past and future rather than just living in the present. Their range of emotions will be more diverse although the child may not completely have the ability to control or understand their thoughts and feelings.

### **Activities that can capture memories**

Finger painting, collage work which is dated and age of child noted. Recording the child's favourite storybook, songs, TV programmes is an activity which will help in giving the child and significant others a sense of themselves.

### **Sharing difficult feelings**

Feeling faces- a good sharing activity. Start by decorating some plain biscuits with a mixture of icing sugar and water to make a thick runny paste. Use sweets and cake decorations to make a face on each biscuit, encourage the child to express different feelings, such as happy, sad, angry, worried, confused etc.

When the biscuits are finished and before they all get eaten discuss with the child the times when they have felt these feelings.

### **Stage of development which maybe equivalent to 6 to 10 years**

By this stage children are developing peer relationships and will be in education.

They are likely to have a sense of routine and have more understanding of their environment and the influences such as seasons, weather, larger world, personal and national events.

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### **Activities that can capture memories**

Fantastic photo frame- Take a clip photo frame, ask the child to select a photo of an important event or perhaps one of them self. The photo that should be a lot smaller than the frame, which should be placed in the middle of the frame. The child can then decorate the border around the photo with symbols that are significant to the day or themselves, e.g. if it was at Christmas they could draw pictures/ use stickers/ cut out pictures that represent a Christmas Tree/ presents/ stocking, etc. If the family is from another faith or culture the child could decorate according to their chosen festival e.g. Divali or the Chinese New Year.

### **Sharing difficult feelings**

Button box: using a selection of buttons ask the child to select different buttons to represent themselves and other members of their family or people that are significant to them (carers, friends, teachers etc.) then ask them to place the buttons on the table, with the button that represents themselves in the middle and the place the buttons representing the different people in the life around this button. Ask them to think about where they place the buttons, putting them in order of who is closest to them nearest their button. The placement of the buttons will be important as well as the size and type of button selected, which might suggest how they view themselves and others.

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Feeling Balloons- ask the child to select the feelings they find difficult to deal with, feelings such as angry, sad, frightened, etc. Write these on blown up balloons and give the child the opportunity to stamp on and burst the balloons or if they cannot do this physically the adult can burst them for them. This can be valuable in acknowledging their feelings.

### **Stage of development equivalent to 10 to 15 years**

By this stage the child may have more sophisticated language skills, or means of non verbal communication and they may be able to understand change and loss. Peer relationships are likely to be becoming more important to the young person. They are beginning to recognise their sexuality and thinking about their identity and orientation. The young person may also have a growing sense of their mortality.

### **Activities that can capture memories**

Memory Bracelets - where the young person can select particular beads which would signify important events, people in their lives, aspects of their personality. For boys, if they do not wish to use beads and would rather have something

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more discrete this can be done using different coloured threads which can be plaited.

Make a time capsule to bury together.....with a 'treasure map'? .....to be opened 5 years, 10 years etc. from now.....

Photo-collage?

What song is top of the charts when a key event happens.....produce a memory poster ....

### **Sharing difficult feelings**

Masks, this activity can be done with both the young person and members of the family. Cut out a mask shape in white card, on one side of the card the young person can draw/paint or decorate the feelings that they keep hidden from most people. These feelings would perhaps be the more difficult ones to share or express, like sadness, anger and fear. On the other side of the mask they can decorate it representing the feelings that are easier to share with others like, happiness, fun and joy. During the making or after the masks are made both sides of the masks can be shared and discussed. If other members of the family can also complete this task, understandings of what feelings are around for each member of that family.

### **Stage of development equivalent to 15 years +**

Young people may be looking to become more independent from their parents or carers. Many young people of their age are of thinking about leaving home or going to college or future opportunities.

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### **Activities that will capture memories**

Developing their own play lists of meaningful music. Home Movies, where they can create a film of what and who are important in their lives.

### **Sharing difficult feelings**

Personal First Aid Kits – We use normal first aid kits to help us if we are injured, this activity is to promote thinking about what helps us emotionally. The purpose of the activity is to raise awareness of positive coping strategies and this can be shared with other important people in the young people's lives so it will improve understanding of what each member of the family need to keep them emotionally healthy.

Some Other Ideas:

A 'person centred planning meeting with friends/ peer group of child/ young person: Create a "wish list" for the young person together: friends then volunteer to enjoy activities and achievements with the young person.

Introduce a "buddy" system. The buddy who is of similar age supports the young person and enables them to engage in age appropriate experiences, activities and shared interests beyond the confines of family and older adults.

## **8. Family Shared Activities**

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As a family devising a family tree will give the child a feeling of connectedness and identity within the family and will be particularly important for the child and their siblings if they are separated.

Looked after children may have had the opportunity for life story work and for compiling of a book about their family and themselves, others may not and this activity would have to be approached with sensitivity.

It would also be important to record important events in the child/young person's life, photograph albums, Life story books, scrap books; videoing can all be used to make sure significant events remain as part of the family's history.

For the families that are grieving after the death of their child, mementos, photographs and recorded memories that are created during the child's life will become precious.

Some families told us that helping their child to make a wish can be very difficult as it involves recognition of their life limiting condition, and staff can play a key role here in encouraging communication and identifying resources. Compiling a video or photo montage or a photo album can help child and carers and or family to recall the happy times.

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Play therapists can help the child and or brothers and sisters to explore and express their feelings in indirect and direct ways. This is skilled work which requires lengthy training and regular supervision and appropriate staff support.

## 9. Transitions

The recognition of an adolescent or young adult to the reality of their life limiting condition takes place at the same time as many other life transitions including sexuality, further education, and employment and to increasing independence from their parents. And also at this time the ways in which services to them are delivered. Health and social work services for adults are provided within different agency and legal structures which often results in the quality and quantity of services being reduced at a time when many young peoples' needs are increasing.

CHAS Youth Adults Council told us:

*"I would love my GP to know me better, and to know more about my condition. It is hard for him because when I was unwell when I was younger, I was always taken straight to hospital."*

*"A summary of my condition to be available for night time if a doctor needed to visit me, or if an ambulance was called would be great – usually either my mum or I have to tell everyone about my condition."*

*"There should be more training for all staff....I have muscular dystrophy and recently I fell out of my electric wheelchair, when paramedics arrived no one knew how to assess me, or how to lift me back into my chair."*

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An increasing number of young people with "complex needs" who require multi-agency support are surviving to adulthood (Scottish Executive 2007).

Young people accessing palliative care have a wide range of conditions with many previously unique to childhood. With advances in medical and nursing care many individuals with complex care needs are now living into young adulthood.

Adolescents often have greater demands on health services due to the fact that they are growing, and developing, but at the same time their disabilities continue.

(Dr R McWilliam, Fraser of Allander Unit, Yorkhill Hospital, Glasgow 2010)

### **One family wrote of their experience.**

*“Louise was born with very complex medical conditions. She was adopted into our family when she was two years old. Her condition was managed by a Consultant Paediatrician and she had appropriate services, which worked very well.*

*As Louise approached eighteen years of age, transition into adult care services began. This was when Louise and our family were totally let down. No consultant was appointed to oversee Louise’s health problems. The local GPs didn’t have the expertise to deal with her deteriorating health.*

*We needed help, but there was none. We were totally isolated, running on energy alone, desperate for answers but none were forthcoming. Had the proper services been in place we, as her parents, would not still be trying to come to terms with not only losing our daughter but also letting her down so badly.”*

The ACT transition pathway was launched in 2007.<sup>9</sup> It was launched in response to growing evidence of the unmet needs and increasing numbers of young

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<sup>9</sup> Reference to follow

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people living with a life limiting condition into adult years. It gives a framework and standards for local service development to respond to three stages of transition: This is equally true for children with palliative care needs.

Rites of passage are no less important for young people with life limiting conditions. It is important to recognise the need to move on with a sharing of significant news and to acknowledge approaching adolescence and in turn approaching adulthood.

The pathway states that moving on, with pro-active planning facilitated by a lead professional must occur even in times of uncertainty, and supported by a comprehensive multi-agency assessment. This must be undertaken within an agreed time frame, after which the young person must be supported in adult services until a sustainable adult service is established. Significant challenges are implicit within this approach not least timing and the ability to commit to dual planning.

This transition can be successfully achieved for young people. We have experience of young people successfully directing their own lives and asserting their wishes for the time of their deaths within their own homes. This has been possible by adopting robust advocacy support and creative multi disciplinary planning and support. Most importantly, the young people have been central to the planning process and their needs and wishes have remained the central focus.

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## **10. Support after death for families and some practical suggestions:**

All families will have immediate and long lasting feelings and will look for different people to support them. Ministers of religion or faith leaders will be able to support and help some families. Others will look to families and friends and professionals.

Some families told us that they felt abandoned after the death of their child.

Some foster carers felt that because they were not birth parents their feelings were considered to be less important by some professionals and also family members.

Each family will find their own ways to grieve and remember their child but families who contributed to this guide gave us the following suggestions.

A Memento book at funeral – this enables people who have cared for or been friends of the child or young person to remember them, a record of a happy or funny moment, a poem or a drawing. At the time of a funeral a family can often be too preoccupied to even know who is attending but afterwards the memento

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book can give an opportunity to appreciate how many people came to pay their respects and cared for the child and family.

Family Photo album – photo albums may be being taken over by photos stored on computer but for many children and adults leafing through an album can still be reassuring and helpful.

Memory box – favourite items of the child or young person and things that other members of family and friends associate with them.

Poster and photo collage – things that remind the family member of person (perfume, jewellery, photos, recipe, music, favourite DVD or movie etc.)

Family event – going to favourite place together and talking about positive memories at that place.

## **11. Supporting staff**

Professional groups have different training, supervision and support as ways of dealing with emotions. Culture, age and gender will also play a part in how staff respond to the sadness which their job can bring to them. Teams can offer support and debriefing to each other and some find that models such as Gibb's reflective cycle can be helpful. (Appendix 1)

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Staff often require support for their work with families and their children. Working in multi disciplinary teams can bring strength and coherence to the help for the child and family but also impose a strain on the professional relationships. Maintaining and recognising professional boundaries is important for long term good joint working.

A professional boundary is the 'line' between the professional and personal relationship. A professional relationship can be defined as that between the family and an individual staff member, in whom the latter has a responsibility for ensuring that objectivity is achieved at all times.<sup>10</sup>

Relationships between families and individual staff members can vary considerably which will involve staff using their professional judgement to ensure

the maintenance of professional boundaries at all times. This is essential in order to:

- 1) Protect families at a time when they may be vulnerable.
- 2) Protect staff from any risk of potential false allegations.

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<sup>10</sup> This draws on policy drafted by CHAS

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Further information about professional boundaries and codes of conduct are available in the NMC Professional Code of Conduct, Scottish Social Service Council Code of Practice and the GMC code of practice. Staff should contact their line, manager, Director of Service area or Human Resources for additional guidance on professional boundaries.<sup>11</sup>

## **Conclusion**

**To follow when we have received comments from the consultation.**

### Appendix 1 **GIBBS REFLECTIVE CYCLE**

Description

(What happened?)

Action Plan Feelings

(If it arose again what (What were you would you do?) thinking & feeling?)

Conclusion Evaluation

(What was good & bad about the experience?)

Description

(What sense can you make of the situation?)

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(Gibbs 1998)

**Stage 1: Description of the event**

Describe in detail the event you are reflecting on.

Include e.g. where were you; who else was there; why were you there; what were you doing; what were other people doing; what was the context of the event; what happened; what was your part in this; what parts did the other people play; what was the result.

**Stage 2: Feelings**

At this stage try to recall and explore the things that were going on inside your head, i.e. why does this event stick in your mind? Include e.g. how you were feeling when the event started; what you were thinking about at the

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time; how did it make you feel; how did other people make you feel; how did you feel about the outcome of the event; what do you think about it now.

### **Stage 3: Evaluation**

Try to evaluate or make a judgement about what has happened. Consider what was good about the experience and what was bad about the experience or didn't go so well

### **Stage 4: Analysis**

Break the event down into its component parts so they can be explored separately. You may need to ask more detailed questions about the answers to the last stage. Include e.g. what went well; what did you do well; what did others do well; what went wrong or did not turn out how it should have done; in what way did you or others contribute to this

### **Stage 5: Conclusion**

This differs from the evaluation stage in that now you have explored the issue from different angles and have a lot of information to base your judgement. It is here that you are likely to develop insight into you own and other people's behaviour in terms of how they contributed to the outcome of the event. Remember the purpose of reflection is to learn from an experience. Without detailed analysis and honest exploration that occurs during all the previous stages, it is unlikely that all aspects of the event will be taken into account and therefore valuable opportunities for learning can be missed. During this stage you should ask yourself what you could have done differently.

### **Stage 6: Action Plan**

During this stage you should think yourself forward into encountering the event again and to plan what you would do – would you act differently or would you be likely to do the same?

Here the cycle is tentatively completed and suggests that should the event occur again it will be the focus of another reflective cycle

Jasper M 2003 Beginning Reflective Practice – Foundations in Nursing and Health Care Nelson Thornes. Cheltenham

Appendix 2 Resources

To follow Legal context for looked after children

Person Centred Case Studies at different ages

Examples of art work exploring feelings and thoughts  
Examples of individual “end of life” plans

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