

Pathways of Care

This Pathway is to be used for children and young people (age 0-19 years) who fulfil the assessment criteria for children with exceptional healthcare needs (CEN). However, professionals may find that they wish to include the larger group of children with complex needs if the Pathway proves to be helpful and encourages better and timely access to service. The pathway should be used by all practitioners who work with children with exceptional healthcare needs and will be made available for families as a source of information.

Please click on the bullet point topics on the right for good practice documents, guidelines and useful links.

More information on the aims of the pathway can be found in [Background](#) and [Acknowledgements](#).

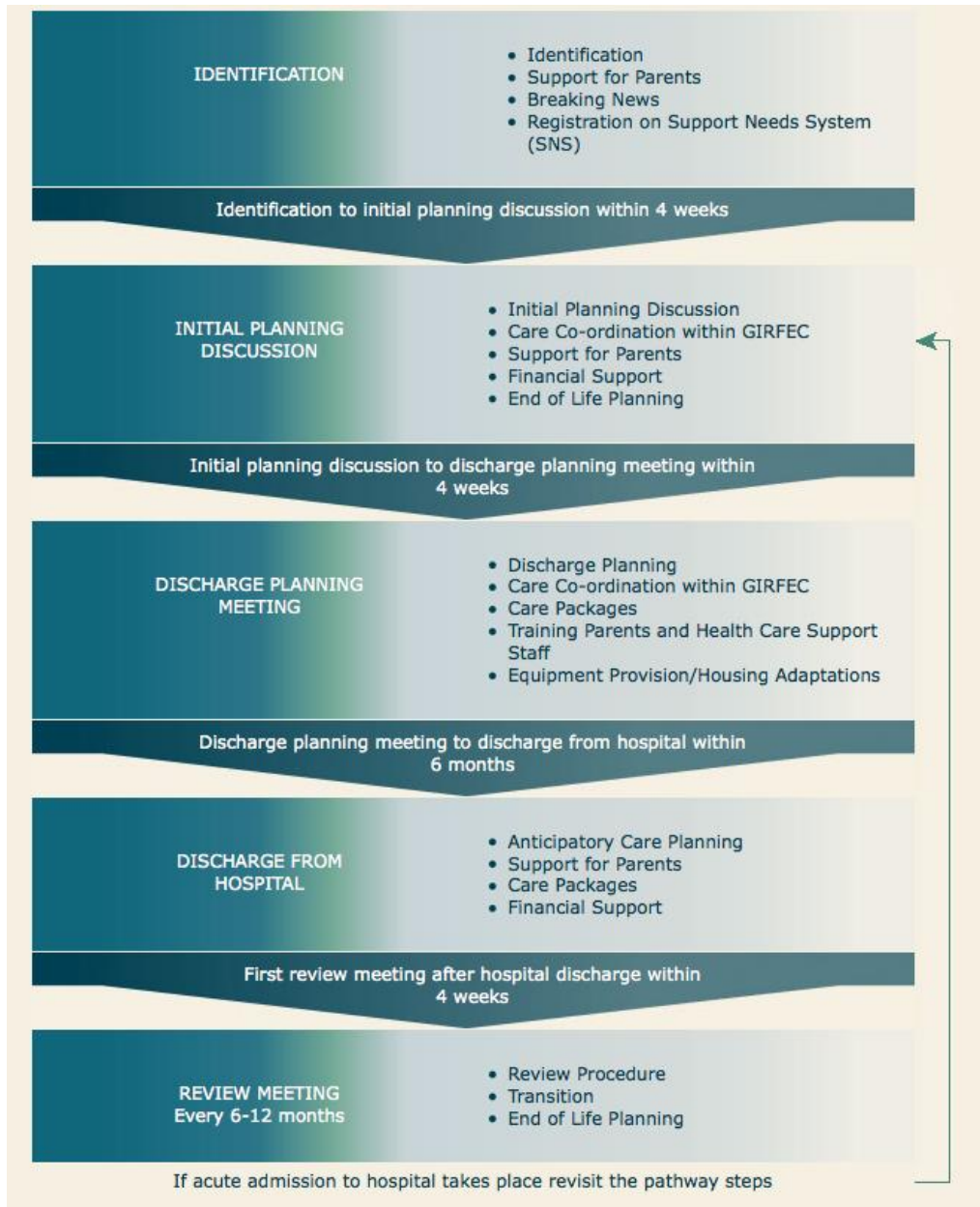


Pathway of Care for Children with Exceptional Healthcare Needs

www.cen.scot.nhs.uk



Pathway of care for Children with Exceptional Healthcare Needs



www.cen.scot.nhs.uk



Pathway for Children with Exceptional Healthcare Needs

- **Who is the Pathway for?**
- **What is the aim of the Pathway?**
- **Why is there a timeline?**

- Home
- About NMCM
- Definition of CEN
- Pathways of Care
- Groups
- Directory
- Network Meetings
- Education - How Does it Feel?

Identification

The Pathway is developed for the use for children meeting the assessment criteria as described below, however our aim is to evolve the document into a Pathway that can support the wider group of children with complex needs. These are the assessment criteria used to identify Children with Exceptional Healthcare Needs:

The six impairment categories used for assessing the children and young people are:

- learning and mental functions
- communication
- motor skills
- self care
- hearing
- vision

A child or young person (up to the age of 19) is defined as having exceptional healthcare needs if they:

- Have severe impairment recorded in at least 4 categories together with enteral/ parenteral feeding OR
- Have severe impairment recorded in at least 2 categories and require ventilation/CPAP

AND the impairments are sustained, lasting for more than 6 months and ongoing.

Children will be identified in a number of ways. They may have a congenital severe health problem or an acute neonatal problem and have complex needs from birth. They may suffer a severe onset condition such as a road traffic accident or a severe infection. They may have a neurodegenerative disorder with gradual decline in health where they then meet the CEN criteria. Ideally children would be assessed using the disability criteria on the national Support Needs System. If the children are assessed using this methodology, the children will automatically be 'flagged up' in the data base and the clinician will be prompted to follow the Pathway. In those areas where the SNS is not in place the health assessment tool can still be used but the children will have to be identified by the clinician as having CEN needs using the defined criteria. Once a child has been identified as being in the CEN criteria an initial planning discussion should take place with a lead professional or key worker identified to do this. Within the hospital this may be the responsible consultant or a senior nurse on the ward or the discharge planning nurse. In each area it is critical that there is a clearly identified person to lead the meetings.

Useful web sites:

- <http://www.cen.scot.nhs.uk>
- <http://www.isdscotland.org/isd/3397.html>

Useful documents:

- [Ulster Complex Needs Report \(June 2007, Northern Island\)](#)
- [Case descriptions of children meeting the Exceptional Healthcare Needs criteria](#)

[Definition of CEN](#)[Pathways of Care](#)[Groups](#)[Directory](#)[Network Meetings](#)[Education - How Does it Feel?](#)

Care Co-ordination within GIRFEC

The child can not be seen in isolation. The impact of the child's needs on the family must be taken into account. Co-ordination of care reduces duplication of effort and therefore makes for a more efficient use of resources. The core team of practitioners involved with the child and family work together to identify needs, co-ordinate assessment processes and plan how and who is best placed to meet the family's needs. Lack of co-ordination adds to the stress for families. The burden of co-ordination often falls onto the parents/carers. A co-ordinated approach is therefore essential to communicate effectively with the family and all the services involved in the care of the child.

Care Co-ordination is the delivery process within Getting it Right for Every Child (GIRFEC) for disabled children and young people. The co-ordinated approach is led by one of the involved practitioners: the key worker (CCNUK) or lead professional (GIRFEC). The terms Lead professional or Key Worker can be used, what is important is the role they provide for the family and fellow practitioners. Their role is not to carry out all the tasks but to ensure that planning and delivery of services are done in an effective and integrated way. Arrangements are discussed by the team as a whole which includes the family, so that decisions and their implications are understood by all. The key worker/lead professional provides:

- A single point of referral and contact for the family and for others in their relationship with the family.
- Emotional support to family members and support to access counselling - this is an essential aspect of the role.?
- Advocacy or facilitate access to it

Care Co-ordination Network UK (CCNUK) is the networking organisation promoting Care Co-ordination and Key Working. They have developed a set of standards for organisational development and key worker practice that is recognised by the Scottish Government (and Westminster and the Welsh Assembly). The self evaluation tool (SET) provides a framework for assessing your service against these standards and free training to use SET is provided.

Useful web sites:

- <http://www.ccnuuk.org.uk>
- <http://www.act.org.uk>
- <http://www.scotland.gov.uk/Topics/People/Young-People/childrenservices/girfec/>

Useful documents:

- [CCNUK membership pack doc \(Dec 2007\)](#)
- [GIRFEC \(Scottish Government Sept 2008\)](#)
- [GIRFEC in Edinburgh \(Scottish Government Nov 2009\)](#)
- [Paediatric Communication Pathway GIRFEC \(NHS Highland Oct 2009\)](#)
- [Integrated Care Pathway \(Merton & Sutton\)](#)
- [Children and Young people with complex needs-Diagnostic and Patient care pathways \(NHS Grampian Nov 2008\)](#)
- [Care Co-ordination Meeting for Children with Complex Health Care Needs-Information for Parents \(NHS Borders\)](#)
- [Long Term Conditions Collaborative-Improving Care Pathways \(Scottish Government 2010\)](#)
- [The Healthcare Quality Strategy \(NHS Scotland May 2010\)](#)
- [Child Locality Team \(MDT\) meeting minutes template \(Dumfries and Galloway\)](#)

Pathways of Care

Groups

Directory

Network Meetings

Education - How Does it Feel?

Care Packages

Deciding on how best to meet the needs of children with exceptional healthcare needs and who should provide the necessary services and funding requires effective integrated working based around a robust joint assessment process. An assessment framework should be used for all children who present with complex needs to assist in determining the contribution of each agency in supporting any additional care requirements. The level of support depends on the nature, complexity and intensity of the needs. A comprehensive, integrated assessment should be used to supply evidence to underpin a care plan to be presented to a complex care panel in order to seek joint funding for a child. There should be a structure for joint agency decision making with appropriate representation.

The agencies involved in supporting Children with Exceptional Healthcare Needs are Health, Social Work and Education.

Children with complex needs have a right to educational provision. This may be in a supported mainstream or special school. The Additional Needs Legislation requires all agencies to work together to best support children in their educational placement. Children can be placed in an educational placement from 3 years old. Most education authorities will provide home visiting teaching support for those who are absent from school for healthcare reasons. Discussions relating to educational support should include: transport to and from school, equipment needed in the school environment, health needs as identified on the health care plan and how this will be provided. Best practice suggests that it is helpful if the person closest to the child is trained to support both their educational and health needs. In some special schools where the health needs of the pupils are high a nurse will be a member of staff.

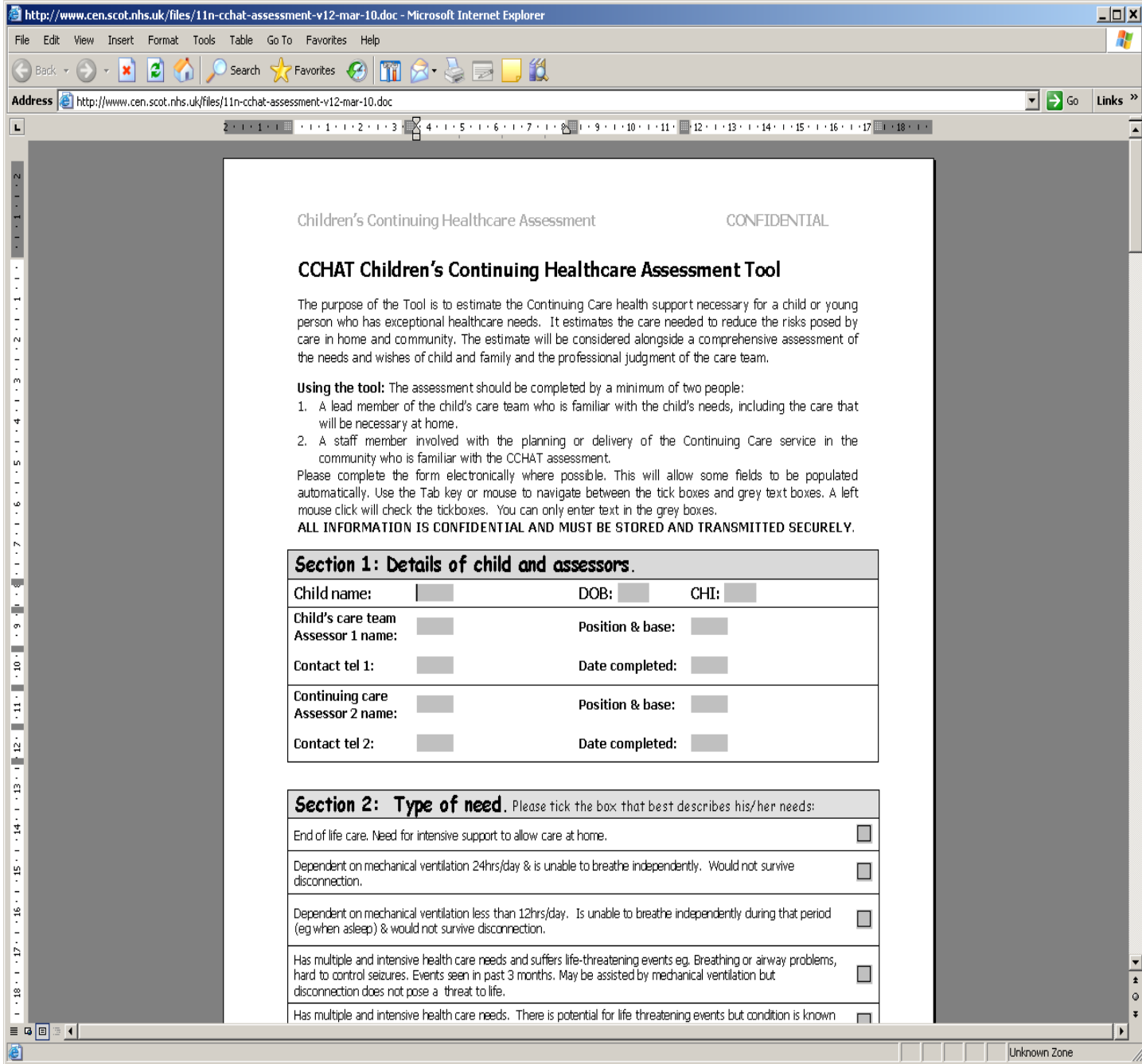
Children with exceptional healthcare needs have specific dental care needs. The dental needs of the child should be discussed with the family involving specialist dentists.

Useful web sites:

- <http://www.sdcep.org.uk>
- <http://www.child-smile.org.uk>

Useful documents:

- [NHS Continuing Healthcare](#)
- [National Needs Assessment Tool for Long Term Ventilated Children in the Community \(Sept 2005, Lanarkshire\) adapted from Bradford CC Tool](#)
- [Complex Care \(Children Services\) Eligibility Criteria \(NHS Forth Valley\)](#)
- [Joint Section 23 assessment \(NHS Forth Valley\)](#)
- [Comprehensive Section 23 Care planning \(NHS Forth Valley\)](#)
- [Level of Needs assessment \(NHS Forth Valley\)](#)
- [Flowchart Complex Care \(NHS Forth Valley\)](#)
- [Continuing care for children with complex needs eligibility criteria \(Bournemouth & Poole\)](#)
- [National Framework for Children and Young People's Continuing Care England](#)
- [Lothian Exceptional Needs Service Eligibility criteria \(August 2010, Lothian\)](#)
- [Using the Children's Continuing Healthcare Assessment Tool \(March 2010, Lothian\)](#)
- [Children's Continuing Healthcare Assessment Tool \(March 2010, Lothian\)](#)
- [Integrated Assessment Framework \(November 2005, Glasgow\)](#)
- [Rationale and procedural guidelines Child Locality Teams \(Aug 1999, Dumfries and Galloway\)](#)
- [Additional Support For Learning \(Contact A Family 2006\)](#)
- [Managing medicines in schools and early years settings \(March 2005, UK\)](#)



CCHAT Children's Continuing Healthcare Assessment Tool

The purpose of the Tool is to estimate the Continuing Care health support necessary for a child or young person who has exceptional healthcare needs. It estimates the care needed to reduce the risks posed by care in home and community. The estimate will be considered alongside a comprehensive assessment of the needs and wishes of child and family and the professional judgment of the care team.

Using the tool: The assessment should be completed by a minimum of two people:

1. A lead member of the child's care team who is familiar with the child's needs, including the care that will be necessary at home.
2. A staff member involved with the planning or delivery of the Continuing Care service in the community who is familiar with the CCHAT assessment.

Please complete the form electronically where possible. This will allow some fields to be populated automatically. Use the Tab key or mouse to navigate between the tick boxes and grey text boxes. A left mouse click will check the tickboxes. You can only enter text in the grey boxes.

ALL INFORMATION IS CONFIDENTIAL AND MUST BE STORED AND TRANSMITTED SECURELY.

Section 1: Details of child and assessors.		
Child name:	<input type="text"/>	DOB: <input type="text"/> CHI: <input type="text"/>
Child's care team	<input type="text"/>	Position & base: <input type="text"/>
Assessor 1 name:	<input type="text"/>	
Contact tel 1:	<input type="text"/>	Date completed: <input type="text"/>
Continuing care	<input type="text"/>	Position & base: <input type="text"/>
Assessor 2 name:	<input type="text"/>	
Contact tel 2:	<input type="text"/>	Date completed: <input type="text"/>

Section 2: Type of need. Please tick the box that best describes his/her needs:	
End of life care. Need for intensive support to allow care at home.	<input type="checkbox"/>
Dependent on mechanical ventilation 24hrs/day & is unable to breathe independently. Would not survive disconnection.	<input type="checkbox"/>
Dependent on mechanical ventilation less than 12hrs/day. Is unable to breathe independently during that period (eg when asleep) & would not survive disconnection.	<input type="checkbox"/>
Has multiple and intensive health care needs and suffers life-threatening events eg. Breathing or airway problems, hard to control seizures. Events seen in past 3 months. May be assisted by mechanical ventilation but disconnection does not pose a threat to life.	<input type="checkbox"/>
Has multiple and intensive health care needs. There is potential for life threatening events but condition is known	<input type="checkbox"/>

[About NMCM](#)[Definition of CEN](#)[Pathways of Care](#)[Groups](#)[Directory](#)[Network Meetings](#)[Education - How Does it Feel?](#)

Financial Support

There are many different sources of financial support available to children with exceptional healthcare needs and their families. Perhaps most important is Disability Living Allowance (DLA) as a lot of other funding is dependent on this benefit. Another important route to resources is an assessment by social work (known as a Section 23). Many families miss out on benefits because the application processes are complex and time consuming. For this reason, it may be beneficial to start looking at the different types of funding with the support of a voluntary organisation.

KINDRED (previously SNIP) has provided a document (in list below) explaining the different sources of financial support these include:

- Disability living allowance (DLA)
- Motability
- Blue badge
- Carer's allowance
- Tax credits (Child Tax Credit and Working Tax Credit)
- Family Fund
- Trust grants
- Assistance with heating bills
- Assistance with Council tax
- Housing support
- New Supply Shared Equity (NSSE)
- Community Care Grants
- Social work assessment
- Direct Payments
- Respite or short breaks

Useful web sites:

- <http://www.direct.gov.uk/en/DisabledPeople/index.htm>
- <http://www.scotland.gov.uk/Topics/Built-Environment/Housing>
- <http://www.funderfinder.org.uk/>
- <http://www.cafamily.org.uk/>
- <http://www.sharedcarescotland.com/>
- <http://www.chas.org.uk/>
- <http://www.familyfund.org.uk/>
- <http://www.johnwatsons.com/>
- <http://www.capability-scotland.org.uk/services.aspx>

Useful documents:

- [Financial support for children with exceptional healthcare needs \(Kindred\)](#)

Breaking News - Children with Exceptional Healthcare Needs (CEN) - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Refresh Home Search Favorites Mail Print Mail Stop

Address <http://www.cen.scot.nhs.uk/breaking-news.html> Go Links

national managed clinical network
children with exceptional healthcare needs

SCOTLAND

Home News Useful Links Contact Us

About NMCM
Definition of CEN
Pathways of Care
Groups
Directory
Network Meetings
Education - How Does it Feel?

Breaking News

Breaking difficult news is an essential part of the pathway for the children with exceptional healthcare needs because it is often a recurrent feature in the lives of these children and their families and this process might be revisited at a number of stages in their lives.

Most parents acknowledge that this is the most difficult time for them to deal with. Respect should be given to the need for parents to deal with difficult information in their own way and time. The following principles may help:

- Who is the most appropriate to break the news (hospital staff/community staff)?
- Be honest and open, remain professional but compassionate as the breaking of such news will be a lasting memory for the family
- Try, if possible, to speak with both parents together and ask if the parent wants another person there for support
- Prepare the physical environment, e.g. privacy, less formal, no interruptions
- Have the baby / child present, if possible
- Use as simple language as possible, assess how much the parents or carers can understand e.g. language barriers, learning difficulties, communication difficulties
- Give good information (do your homework) but admit if you don't know the answer to a question
- Have details of any resources to hand (websites/information packs, support groups, contact personnel)
- Have another person working already with the team with you ? to be available to the parents to go over what was said
- Limit the professionals to those really necessary e.g. families may be overwhelmed by numbers present
- Be available to answer further questions. Sometimes questions already asked need answering again
- Allocate a date /time for a follow-up session , allow time for the family to take it all in
- Record a summary of the session with details of the news given and the family response

Useful web sites:

- <http://www.act.org.uk/>
- <http://www.dsscotland.org.uk/professional/breakingthenews>
- <http://www.skillscascade.com/badnews.htm>

Useful documents:

- [Framework for Sharing Significant News \(July 2010, Scottish Children and Young People Palliative Care Network\)](#)
- [Breaking Bad News Regional Guidelines \(February 2003, Northern Ireland\)](#)
- [Guidelines on the Breaking of Bad News \(March 2010, NHS Yorkshire\)](#)
- [Informing Families of Their Child's Disability-National Best Practice Guidelines \(2007, Ireland\)](#)
- [Good Medical Practice in Paediatrics and Child Health \(May 2002, UK\)](#)

Done Internet



Professionals > Breaking the News

Breaking the News

How parents are told their baby has Down's syndrome is very important. Medical professionals should take a sensitive, compassionate approach, taking their lead from the parents. In lot does happen, however many of our members told us that the way in which they were told was negative and had a profound and lasting effect on them.

Our Breaking the News DVD films a few families talking about how they were told and how they feel. For some people having a baby with Down's syndrome is upsetting, but for some it makes no difference to them; it's important that medical professionals try to distinguish between different reactions and deliver the news accordingly.



[Please download Adobe Flash Player to see this content.](#)

Press play to get a sneak preview of our Breaking the News DVD - filmed and directed by Telfer. The full DVD is 13 minutes and will form part of our ongoing training.

A FRAMEWORK FOR SHARING SIGNIFICANT NEWS

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

Sharing the significant news to a family that their child has cancer or 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).

"I think that conveying difficult news to parents is just as much of an art form as doing an operation and it's just as important to be self-critical"

Professor Sir David Hall

At such a difficult and stressful time families need honesty, respect and, above all, time from the 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. This was highlighted in a report by Leonard in (1994) called: 'Right from the Start', which has now become a national initiative that aims to promote good practice at the time news is shared with families.

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

Training Parents and Health Care Support Staff - Children with Exceptional Healthcare Needs (CE - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Refresh Print Mail Stop

Address <http://www.cen.scot.nhs.uk/care-support-staff.html> Go Links >>

About NMCM
Definition of CEN
Pathways of Care
Groups
Directory
Network Meetings
Education - How Does it Feel?

Training Parents and Health Care Support Staff

Training parents and carers to feel confident in dealing with the technical aspects of the care for their child is an essential step in preparing the home support plan. Healthcare support staff need to be appropriately trained to allow timely discharge of children with exceptional healthcare needs. In addition staff from Education or Social Work who care for a child with exceptional healthcare needs will receive healthcare training. Standard well tested training guidelines are available across Scotland. Often, parent / carer involvement in training of support workers can be very helpful. Both parents and care support staff should receive continued support after training is completed.

Health support staff should have access to:

- Professional development support
- Pastoral support
- Clinical supervision
- Peer support
- Named/Key contacts
- Achieving competence in care requirements
- Maintaining competence e.g. Annual updates

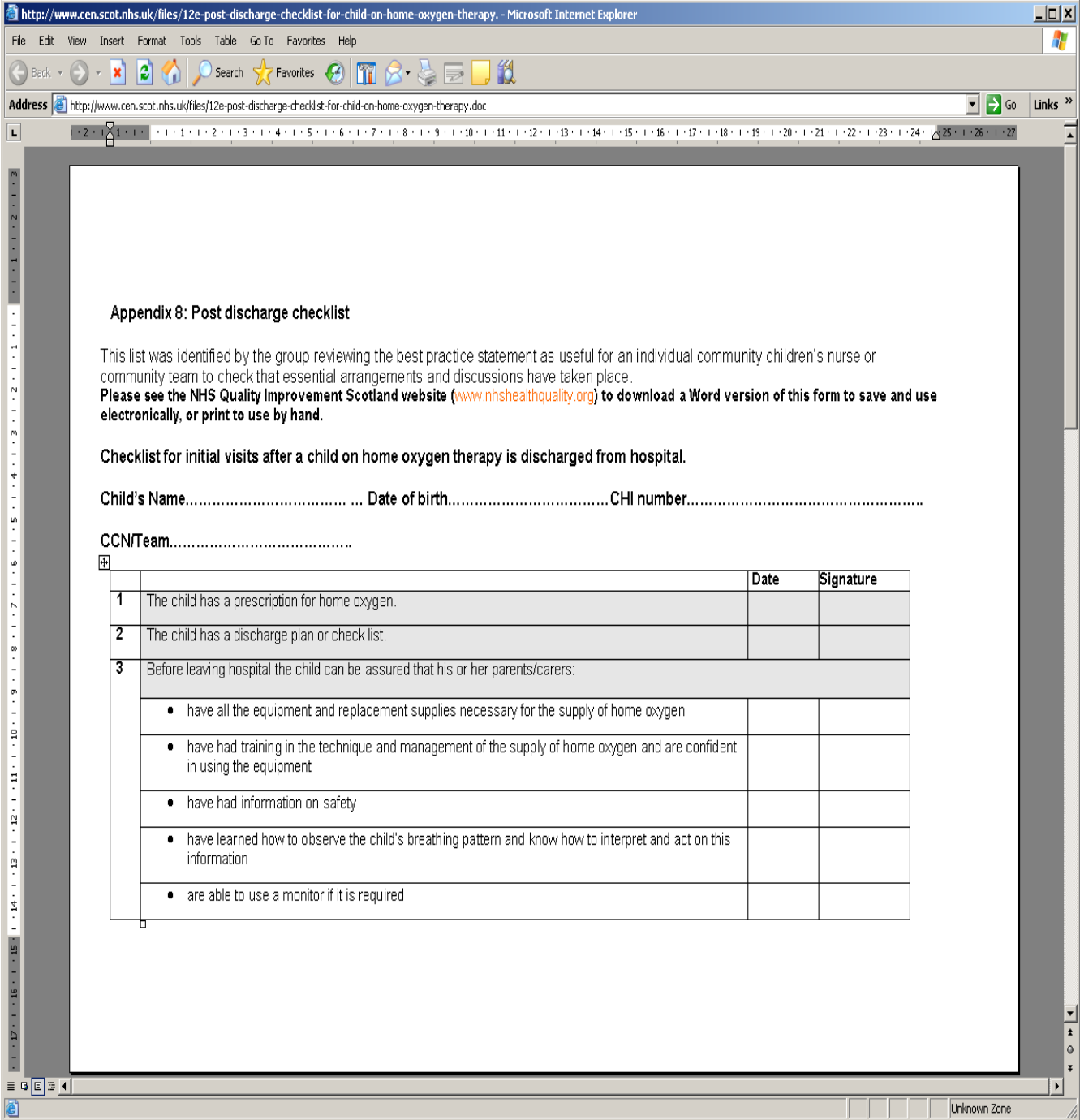
Useful web sites:

- <http://www.cen.scot.nhs.uk/page-20100202-160346.html>
- <http://www.nhshealthquality.org/nhsqis/>
- <http://www.nes.scot.nhs.uk/>
- <http://pamis.org.uk/page.php?id=20>

Useful documents:

- [Enteral Feeding Guidelines \(Lanarkshire Feb 2009\)](#)
- [Caring for the child/young person with a tracheostomy \(NHS QIS Sept 2008\)](#)
- [Home oxygen therapy for children being cared for in the community \(NHS QIS March 2010\)](#)
- [Post discharge checklist for child on home oxygen therapy \(NHS QIS\)](#)
- [Sample training record for person caring for a child receiving long-term oxygen therapy in the community setting](#)
- [Home Oxygen- Template for useful contact numbers for parents & carers](#)
- [Paediatric enteral feeding guidelines \(Dartford & Gravesham Jan 2007\)](#)
- [Caring for children and young people in the community receiving enteral tube feeding \(NHS QIS Sept 2007\)](#)
- [Nastrogastric and Gastronomy tube feeding for children being cared for in the community \(NHS Lothian Jan 2003\)](#)
- [Integrated Community Children's Service - Gastrostomy Button change leaflet \(NHS Lanarkshire, June 2009\)](#)
- [Integrated Community Children's Service - Nasogastric information leaflet \(NHS Lanarkshire, June 2009\)](#)
- [Integrated Community Children's Nursing Service: Passing a Nasogastric Tube Information Leaflet \(NHS Lanarkshire, June 2009\)](#)

Done Internet





Anticipatory Care Planning - Children with Exceptional Healthcare Needs (CEN) - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Refresh Home Search Favorites Mail Print Mail Stop

Address <http://www.cen.scot.nhs.uk/care-planning.html> Go Links >>



Home News Useful Links Contact Us

- About NMCM
- Definition of CEN
- Pathways of Care
- Groups
- Directory
- Network Meetings
- Education - How Does it Feel?

Anticipatory Care Planning

Anticipatory planning for acute readmission to hospital should take place in case the child needs to go into hospital unexpectedly. This should be included in the initial discharge plan. It can be very helpful for parents to have a short summary of their child's main health problems, current medication and possible emergency needs. Parents find it very distressing to have to repeat complicated histories in relation to their child particularly in acute situations. Before leaving hospital a plan should be put in place for the acute care of the child.

- When should the GP be contacted?
- When could the specialist nurse help?
- When should the Out of Hour's service become involved?

Currently, work is progressing on an electronic record that will be accessible to Primary Care NHS24, Out of Hour's services and ambulance services and in the future with the A & E hospital departments. At the moment, GP and paediatricians recommend that parents hold a copy of the up to date information about the healthcare needs of their child to support the communication with all the professionals involved in acute care.

Useful documents:

- [Special Notes Form \(July 2010, NHS Lothian\)](#)
- [Personal Critical Health Information \(Scottish Children and Young People Palliative Care Network\)](#)
- [CHIP Update Record \(Scottish Children and Young People Palliative Care Network\)](#)
- [Care Support Devices Equipment CHIP tool \(Scottish Children and Young People Palliative Care Network\)](#)
- [Home care management template \(Scottish Children and Young People Palliative Care Network\)](#)
- [Guide for using home care management template \(Scottish Children and Young People Palliative Care Network\)](#)

Copyright © 2009-2010 NHS. All Rights Reserved.
[Accessibility](#) · [About This Site](#) · [Site Map](#) · Web Site Last Updated 23 September 2010.
Powered by [Digital Web Limited](#)

Internet

Transition - Children with Exceptional Healthcare Needs (CEN) - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Refresh Mail Print Send To

Address <http://www.cen.scot.nhs.uk/transition.html> Go Links >>

Pathways of Care Transition

Groups

Directory

Network Meetings

Education - How Does it Feel?

Transition is a challenging process because of the different methods of delivery of service in the paediatric and adult services. Parents and the young person can find the moving to different services and the building of new relationships with a range of different professionals daunting. Transferring from child to adult services can bring additional stresses and anxieties to a family. The transition process can be improved by using a transition team to identify the young person's on-going needs and then look at how there can be accommodated within the adult service.

Key themes:

- Start planning early
- Get information about the choices available
- Involve parents and the child as appropriate in all discussions
- Identify what needs to change
- Determine who will provide that service in the 'adult world'
- Inform acute hospital LD Liaison Nurses (if service exists) to do preparation work for any hospital admissions in adult service
- The adult world operates differently: a lead professional transition worker will facilitate the process

Parents and carers need to be well informed about the changes in legal rights and responsibilities with the adults with incapability legislation for young adults over the age of 16 years old.

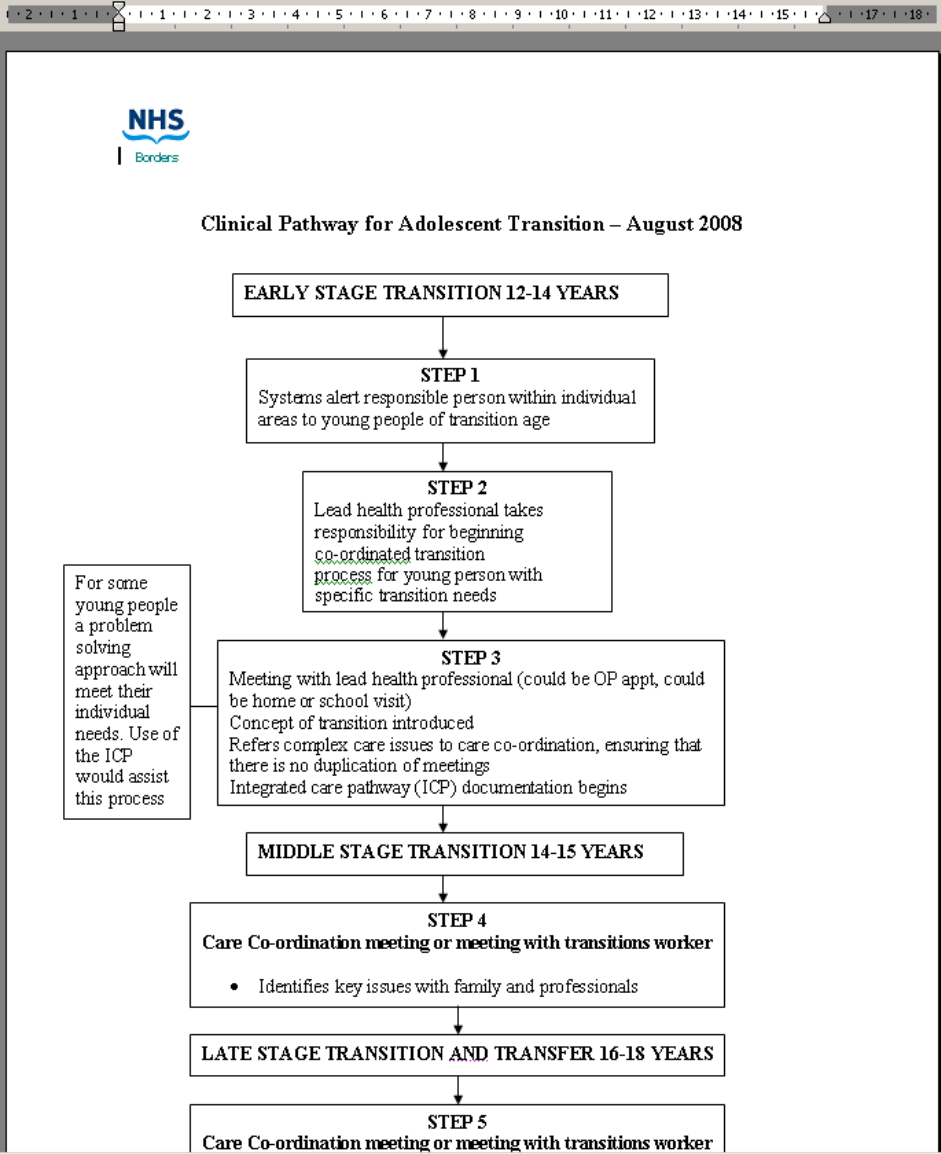
Useful web sites:

- <http://www.pamis.org.uk/page.php?id=30>
- <http://www.act.org.uk/shop.asp?itemid=127&itemTitle=The+Transition+Care+Pathway&ion=143&ionTitle=Resources+and+shop>
- <http://www.signpost-online.co.uk/>
- <http://www.transitioninfonetwork.org.uk/>
- <http://www.scotland.gov.uk/Topics/Justice/law/awi>

Useful documents:

- [Vision for Transition multi agency project \(July 2008, NHS Highlands\)](#)
- [Integrating Services for Young People and Young Adults with Additional Support Needs as a result of Disability and/or complex health \(2008 NHS Highlands\)](#)
- [Transition moving on well \(2008, Department of Health, England\)](#)
- [Transition from child to adult health care services, issues and recommendations for practice \(Lothian\)](#)
- [Transition Bridge pathway between GIRFEC child's plan & adult's personal plan \(NHS Highland\)](#)
- [My transition guide \(June 2008, NHS Highland\)](#)
- [GIRFEC Integrated Transitions and Pathway Maps \(Sept 2009, NHS Highland\)](#)
- [Clinical Pathway for Adolescent Transition \(Aug 2008, NSH Borders\)](#)
- [Transition to adult health services care pathway \(NHS Borders\)](#)
- [Notes regarding clinical pathway \(NHS Borders\)](#)
- [Integrated Care Pathway, Managing Transitions to Adult Service \(July 2009, Northern Island\)](#)
- [Adults with Incapacity \(NHS Lothian\)](#)
- [Think Transition \(Royal College of Physicians of Edinburgh \(2008, Edinburgh\)](#)
- [Information about Adults with Incapacity Act AWIAC](#)
- [Transition Service- Referral guidelines \(Lothian\)](#)
- [Transition Planning Guidelines \(Sept 2010, Lothian\)](#)

Internet



[Home](#)[About NMCM](#)[Definition of CEN](#)[Pathways of Care](#)[Groups](#)[Directory](#)[Network Meetings](#)[Education - How
Does it Feel?](#)[News](#)[Useful Links](#)[Contact Us](#)

Review Procedure

This is not a 'one off process' and each time there is a change in the child's situation with or without an acute admission a review of their situation using the Care Co-ordination approach should occur. Most of these children will benefit from at least a 6 monthly review of their situation.

The following people could be involved in the review:

- Parents
- Lead professionals / key worker
- Health visitor
- Children's Community Nurse
- Social Worker
- Homevisiting Teacher
- Child and Family Centre Staff
- Nursery School Staff
- Educational Psychologist
- Community Paediatrician
- GP
- OT/Physiotherapist/SALT
- Specialist Nurse
- Home Support Worker
- Paediatric Specialist
- Housing Representative
- Transition team
- Social Work

The aim is to review and report on:

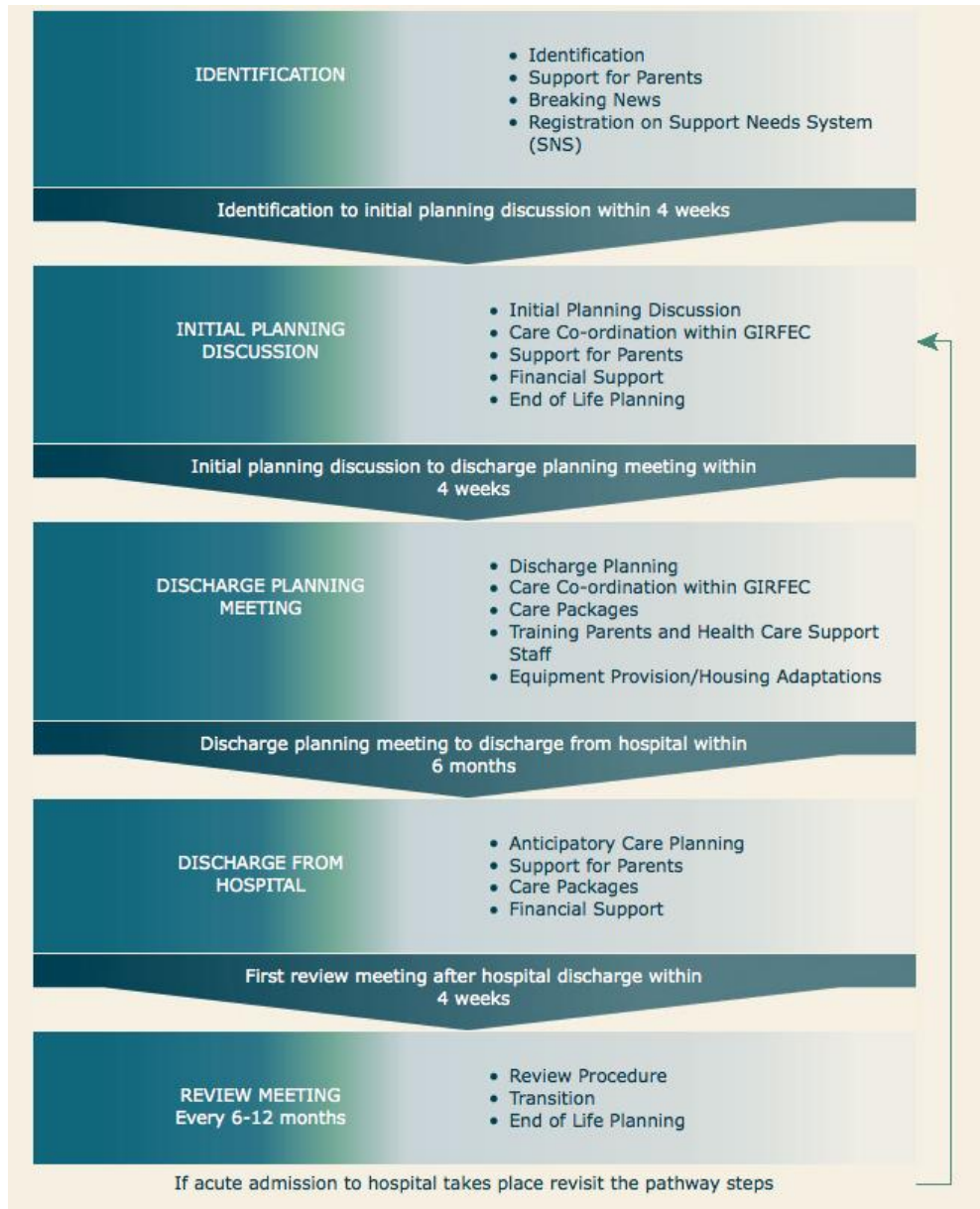
- Home situation
- Preschool / School situation
- Emergency Care
- GP / Primary care involvement
- Dental care needs
- Specialist involvement

How will we measure effectiveness of the Pathway?

Initial measurements will relate to:

- 1) Effective identification and early support to parents of CEN child.
- 2) Time from identification to initial planning discussion.
- 3) Time from discharge planning meeting to discharge to home.
- 4) Evidence of use of care plans for care at home, social / education settings and use of acute care packages.
- 5) Evidence of effective care coordination meeting model in place for each child within the GIRFEC model.
- 6) Recording frequency of admissions to hospital.
- 7) Evidence of access, if appropriate, to palliative care systems.

Pathway of care for Children with Exceptional Healthcare Needs



www.cen.scot.nhs.uk



Pathway Development Group NMCN CEN:

Dr Patricia Jackson, Lead Clinician NMCN CEN

Dr Marit Boot, Manager NMCN CEN

Claire Edwards, Training Consultant and Parent

Jacqueline Reilly, Children and Young People Discharge Nurse Coordinator, Greater Glasgow and Clyde

Francis Edwards, Palliative Care Nurse Consultant, Grampian

Brian Samwell, Wellchild Nurse

Gordon Linton, Nurse Consultant, Lothian

Sophie Pilgrim, Kindred (SNIP)

Joanna Young, Community Children's Nurse, West Lothian

Alison Siddons, Education, Dundee Council

Pauline Smith, PAMIS

Anne Gornall, Senior SGDP in Paediatric dentistry, NHS Highland

Pat Rankin, Community Children's Nurse, NHS Highland

Additional contributions provided by:

John Welsh, Social Work & Health, Angus

Donella Clark, Children with Disabilities Team, Aberdeenshire Council

Lesley Horsburgh, General Acute Higher Specialist Nurse, Borders

Katie Rigg, Palliative Care Nurse Consultant, Tayside

Annamarie King, Paediatric Complex Care, Forth Valley

Dr Jacqueline Crum, Consultant Paediatrician, Grampian

Margaret Johnston, Children's Community Nursing, Lanarkshire

Carol Cameron, Gastroenterology Nurse, Grampian

Sandie Young, Interagency Nurse Consultant Children and Families, Highland

Anne Wilson, Development Officer, Action for Sick Children Scotland

Maggie Roscoe, Team leader Children and Families OT Team, Lothian

Carol Rice, Social Work, Edinburgh

Carolyn Baxter, Community Children's Nurse, Lanarkshire

Dawn Moss, Children and Young People Services, Borders

Monica McTurk, Chief Speech and Language Therapist, Head of Special Needs, Dumfries and Galloway

Mark Bevan, Capability Scotland

Dr Sally Harkness, GP, NHS Grampian

Dr Una Macfadyen, Consultant Paediatrician, Forth Valley

Karen Sinclair, Palliative Care Nurse Consultant, Greater Glasgow & Clyde