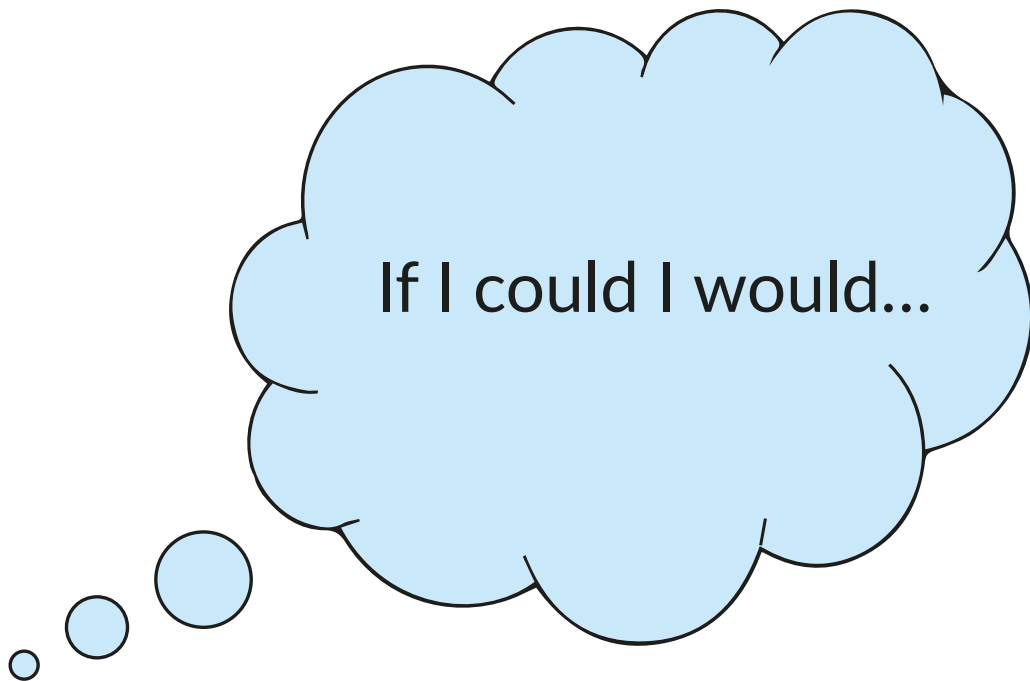


Integrated Person-Centred Planning for Children, Young People and Families Receiving Palliative Care

GUIDANCE AND TOOLKIT

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FOREWORDS

I commend this 'toolkit' to you; it is child-focussed and very family-friendly. Whilst it provides a comprehensive framework, it is not daunting and the information gathered can easily be updated as needed. It is current and very relevant and the format provides an approach to support coordination between services, reviews and transition planning for children, young people and families. It provides a very positive way to tackle some of the challenges and difficult conversations within children's palliative care in a structured, positive and accessible way.

*Clare Periton
Chief Executive, Helen & Douglas House Hospice*

This practically focussed toolkit for integrated, person-centred planning for children, young people and their families is well aligned with the recent NICE Guidance on End of Life Care for Infants, children and young people with life limiting conditions: Planning and management (NG 61). It provides a practical example of how the guidance on 'Information Sharing', 'Communication', and 'Advance Care Planning' can be put in to everyday practice. In the related Quality Standards (QS 160), NICE have chosen to further highlight the importance of care planning and the active involvement of patients and their families in the process, making this document a helpful vehicle for quality improvement.

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Integrated Person-Centred Planning for Children, Young People and Families Receiving Palliative Care: Guidance and Toolkit

This toolkit supports the implementation of recommendations in the NICE guideline on end of life care for infants, children and young people with life-limiting conditions. It also supports statement 1 in in the NICE quality standard for end of life care for infants, children and young people.

*National Institute for Health and Care Excellence
January 2018*

INTRODUCTION

Support planning for children receiving palliative care, for those living with a life-threatening or limiting illness and their families, using practical person-centred thinking approaches

Person-centred planning (PCP) goes back a long way and has strong links to work promoting independent living (Wolfsenberger 1972). It is based on a social model of illness or disability using a positive, strengths-based approach to support care planning. PCP is defined by O'Brien and Lovett (1992, p.5) as approaches for 'organizing and guiding community change in alliance with people with disabilities and their families and friends... The person at the focus of planning, and those who love the person, are the primary authorities on the person's life direction'. Instead of giving a definition, the Health Foundation (2014) describes 'four principles of person-centred care' which are:

1. Affording people dignity, compassion and respect
2. Offering coordinated care, support or treatment
3. Offering personalised care, support or treatment
4. Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life.

PCP developed because people with disabilities or long-term conditions often found it difficult to access services, opportunities and experiences and when doing so had to 'fit' into whatever was provided, whether appropriate or not. This approach now has a broader role in integrated care planning, delivery and support across all age groups in many settings. It is important to acknowledge that the PCP approaches and tools exemplified in this guidance are well established, They have been developed, researched, tested, refined and recommended over a number of years by many credible sources including the Department of Health (DH) (2010a) and Helen Sanderson and Jaimee Lewis (2011), and are used in health and social care services.

This toolkit aims to help children and families receiving palliative care, and services supporting them, to use person-centred practice. Together for Short Lives (2017, p.1) describe palliative care for children and young people as:

an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

The Department of Health (2008, p.14) recognises that palliative care for children ‘starts at diagnosis and is about improving life experiences for children and young people with life-limiting and life-threatening conditions’. The examples included in this guide are useful for those receiving or ‘living with’ palliative care support and their support service, to ensure that quality of life is always considered for the child and family along with their health and safety needs. By adopting a more person-centred approach to communication and in planning care, the hope is that this approach will help in other situations when families are involved in planning ahead, such as preparing their child for transition to adult life.

Person-centred planning seeks to create a picture of an individual’s life within their family/local community and their choices/hopes, and describe the actions needed to keep moving them in their chosen direction. It provides an approach to care that leads to positive changes in people’s lives and services (Ritchie *et al.* 2003). It is about understanding the individual/child/family’s values and needs, and how they may be met, rather than thinking about how they will fit into the existing service system. It reaches far beyond service responsibilities to encourage empowerment by considering the actions and responsibilities of the individual child/young person, family and their own personal support network. This is essential for children and families receiving palliative or end-of-life (EoL) care.

Person-centred planning uses a flexible, responsive approach to meeting an individual or family’s needs and responds to changing circumstances, guided by the principles of good practice rather than a standard procedure (Sanderson 2000). Person-centred planning is simple and effective. This can help services identify and record unique, useful and important information about an individual and their family, which can prove especially helpful when reviewing ongoing management and palliative support or when having conversations about advance care planning (ACP) or EoL care by:

- providing a clear and practical *focus for discussion* between families and support services
- assisting with identification of *outcomes*
- promoting the use of active listening
- recording information in the child or family’s words
- encouraging positive thinking and highlighting individual strengths
- enabling staff and families to find different ways of working, generating creative ideas
- empowering children, young people and their families to be involved, take some control or understand their responsibilities
- helping families to make the right connections
- supporting challenging conversations such as ACP discussions and parallel planning for emergency or end-of-life care.

The word 'child' is used throughout this guidance to refer to babies, children and young people. The word 'support' is used in this guidance to refer to any services, organisation or individuals who provide help for a child/family formally – for example, all members of the multidisciplinary team (MDT) across education, health, social care, charity – or informally, such as family, friends, clubs, etc.

This guidance and toolkit can be used to help put recommendations from the recent NICE Guidance on End of Life Care for Infants, children and young people with life limiting conditions: Planning and management (NG 61) into practice – particularly with regards to information sharing, communication, advance care planning (ACP) and encouraging user and family involvement. This guidance can be used in conversations or to support care planning to help those delivering or receiving longer-term palliative care, emergency or parallel planning. It supports those thinking through ACP, when considering future wishes or choices about where a child may be cared for and who may be involved in giving that care. It can support EoL care planning and delivery. It introduces a number of well-known and well-used person-centred approaches which enable services, families and support networks to think together, have meaningful conversations, gather useful and unique information and help develop care and support plans which aim to achieve a child/young person's and family's desired outcomes/goals and to ensure they live well.

CORE PERSON-CENTRED TOOLS

The first section of this guidance covers a few core person-centred tools that can be used to support children and families receiving palliative care such as:

- *Like and admire* – this conversation can be used to promote positive thinking about a child.
- *Important to and important for* is the principle of how to identify what is important *to* a child/family to achieve happiness/wellbeing and describe good support *for* them to keep healthy and safe.
- *Relationship circles* are used to map and record important relationships – contact information for those people, organisations or services giving a child/family formal and informal support.
- *Working and not working* helps to review a child/family's support and identify any areas for improvement or change. This can help identify outcomes and support reviews of care.
- *One-page profiles* provide a summary of important information about a child. This is useful in any setting to summarise essential care required by the child/family.

1. LIKE AND ADMIRE

Describing what you 'like and admire' about a child is a simple person-centred conversation. This can be used at the beginning of review meetings and gives an opportunity for anyone who knows or supports a child/family to describe in their own words what they like and admire about them. This promotes positive thinking about a child, describing their personality, skills and abilities, and can be included in 'one-page profiles' or other care and support plan documents.

Example: What people said they liked and admired about Hannah at one of her person-centred review meetings at school.

What I like and admire about Hannah is:

- Her relationship with her mum, dad, sister and family.
- She has lots of personality with a smile to melt your heart.
- Hannah is very welcoming and a delight to be around.
- School wouldn't be school without Hannah.
- She enriches everyone's lives.
- Hannah has a strong personality (and will be a strong woman!).
- She is very affectionate with a wicked sense of humour.

2. IMPORTANT TO/IMPORTANT FOR

This tool encourages a way of helping everyone to think about what is *important to* a child or family to promote their wellbeing and ensure they are happy, peaceful and fulfilled (spiritual, emotional and psychological support) and what support is *important for* them to ensure good support to maintain their health and safety. It is important that these elements are balanced if holistic care is to be delivered. If considered in detail, the information recorded can be used to build a 'care plan' which describes all the care and support required by a child. A medication chart would also be needed to support the plan if medications are required.

Important to you for your wellbeing (what you enjoy and what makes you feel happy, peaceful and valued)	Important for you for your health and safety (what good support looks like for you)

Example: A small section of Hannah's important to/for care plan written for use at home to support overnight carers. 'Focusing on things important to and for Hannah helps make things work better for her and for our family' (Rachel Tyler).

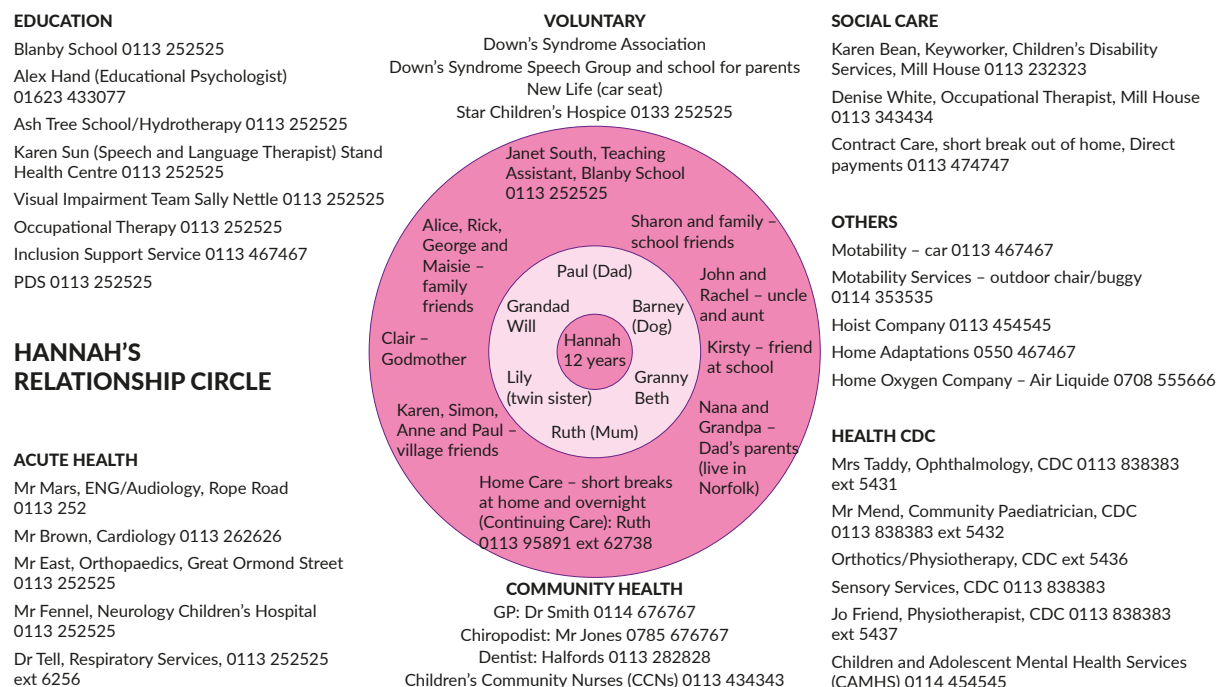
What is important to me – what makes me feel happy and valued	Important for me – what good support looks like to keep me safe and healthy
<p>Familiar routines are important as I like to know what is going to happen.</p> <p>Morning routine: If I wake up in the early hours of the morning, please remove my oxygen and take the probe off my foot but don't turn on the light or open the curtains. Give me a few soft toys to play with, but leave me in my bed and shut the door. If I wake up later, it takes me a while to wake up properly. I like to be left in my bed. Once I am ready to get up, please change my nappy and take me to the kitchen for breakfast.</p> <p>Getting dressed: I get dressed after my breakfast. I will generally let you get me dressed, as long as you don't rush me.</p> <p>Lunchtime: I eat lunch about 12–12.30pm.</p> <p>After school: When I get home from school, I am usually happy just sitting on the sofa. I often don't want any toys to play with.</p> <p>Tea time: I have tea around 4.30–5pm.</p> <p>Getting undressed: Please ask me to put my arms up so that you can undress me. You can also gently encourage me to put my arms up by tapping my elbows. Please do not pull my arms up.</p> <p>Bath time: Before my bath I sit on the toilet. I like having a bath, but I hate having my hair washed. Please help me to wash myself. Look out for flying sponges! When it is time to come out of the bath, please dry me. Rub E45 cream on my arms, legs, face and back.</p> <p>Bedtime: Usually around 7pm, but if tired I will go earlier. I have a drink of milk and a story before I go to bed, with my hip brace on. Sometimes I decide I want to play. I can be active for hours. It is best if you leave me in bed to play. I may shout, but I am quite happy. I sleep with my little moon light on all night. I have my sensory lights on when I go to bed but please turn them off when I am asleep. If I keep shouting, I may have been to the toilet and need my sleeper pants changing. Sometimes I just want to be reassured that you are there. If I have been shouting for a while, please try to settle me and give me a cuddle. If I fall asleep right at the bottom of the bed, please lift me to the top of the bed and lay me on my front when I am asleep. You will know when I am asleep because you will be able to move me easily without me waking up. Please put on my oxygen and saturation monitor.</p>	<p>Support for my breathing</p> <p>Overnight oxygen: I have overnight oxygen every night when I am asleep. I do not like a face mask on my face, so the mask is placed close to my face but not touching it. The oxygen is delivered via a concentrator (supplied from Air Liquide).</p> <ul style="list-style-type: none"> • I have a high-flow concentrator through which I have 6 litres of oxygen if I have a cold or breathing is difficult. • I have a low-flow concentrator when I am well. I have up to 3 litres. <p>Saturation monitor: I have a saturation monitor.</p> <ul style="list-style-type: none"> • The limits are set for my heart rate at 125 and 46. The limits for the oxygen are set at 100 and 93. • The volume on the monitor is set on level 1 as the alarm is very loud and disturbs my sleep. <p>Once I have fallen asleep at night, please wait about 20–30 minutes and then put on my oxygen mask and my O2 saturation monitor probe on my toe. I am normally settled in my sleep for a few hours. However, I do wake very easily so you need to be VERY quiet.</p> <p>CPAP – Nippy Junior</p> <p>Night: I should use my Nippy every night, but I don't like it. I will keep it on for short periods only when I am awake.</p> <p>Daytime: I use my Nippy if I am awake and I have a 'floppy episode'. If I become very pale, lose my colour, become floppy and unresponsive and my breathing seems shallow, please use my CPAP. It helps to keep my lungs open and you can deliver oxygen through it as well. If I do not come round after 20 minutes, you might want to ring for an ambulance.</p> <p>Salbutimol Inhaler: I have 2 puffs of my inhaler through a spacer, to help me with my breathing if I can't stop coughing or want to cough but I am not able to do so effectively.</p>

3. RELATIONSHIP CIRCLES

The relationship circle provides a way to visually map out all the important people in a child/family's life. It can be used as a contact sheet and names of people or services can be added along with contact details. Start by drawing some circles on a blank page. Put the child's name in the middle circle. The second circle can be used to identify people who are the closest to the child/family and offer ongoing support. This is close family, parents/carers, siblings, grandparents and close friends whom the family trust and respect and may rely on for support. These people are significant as they will often offer emotional, psychological and/or spiritual support to an individual or the whole family.

The third circle records the names of other people who are very important to the child/family such as more distant relatives – aunts and uncles, cousins, friends, etc. These are individuals who once again are trusted and may be involved in supporting the child/family. Some service providers who give additional levels of one-to-one support or spend significant amounts of time with a child, such as teaching assistants and home carers, may be named in this circle. These may be able to offer objective support or take notes at meetings or when bad news is broken. A further circle can be added for more distant relatives, friends and services if required.

Example: Hannah's relationship circle. 'Information about Hannah is presented in a way that is easy to follow. The details of all contacts are in one place which helps our family and other services to see at a glance who is involved in her care' (Rachel Tyler).



The area outside the circles can be used to record people, services and organisations involved with a child/family. These may be services that support the family from social care, education, health voluntary sector and also equipment support services, leisure clubs and social groups, etc. It is helpful to add in titles or roles and contact details such as address, telephone numbers and email addresses.

4. WORKING/NOT WORKING



This tool can be used to help a child/family think about and review from their perspective what is going well or ‘working’ and identify what is not working so well in their lives generally, and to identify support or care that is working well or highlight care that needs to be changed or improved. When things are not working well, it causes a child unnecessary upset or frustration.

It can be really helpful for a family to get other people’s perspectives when considering what is working and not working for them. This may be achieved by involving someone else in care reviews/discussions, such as a family member or a close friend. The relationship circle helps to identify those trusted individuals who can provide objective views and support such situations.



First consider what is ‘working’ well with regard to care, support and life in general. Do the family or others need to do anything to ensure these things keep happening? Keep a note of any support that needs to remain unchanged. Then consider what is ‘not working’. This helps to identify the care or support that may need to be modified or changed. Again, keep a note of this as you agree and update the care/support plan.

This is a useful tool or conversation for a family to use ahead of any appointments or review meetings with health care teams or other services, to help them focus and lead the conversation and ensure that things a child or family want to discuss or deal with remain on the agenda and do not get missed.

Using this way of thinking makes us aware of what is working. We can then ensure we keep it in place. It also helps us clarify in our own minds what is not working. We then feel more able to identify the areas in which we need to ask for help when attending Hannah’s reviews and appointments. (Rachel Tyler)

 Working	 Not working
Action: What I/we want or need to change:	

Example: A section of a 'Working/not working' document for Hannah, written by her mum to take to one of her multi-disciplinary (MDT) review meetings.

 Working	 Not working
<p>Buggy: Buggy is really great and helps us get out and about.</p>	<p>Will soon outgrow current buggy and readjustment is needed.</p>
<p>Boots/splints: Boots and splints are fine. Understand ongoing arrangements for follow-up and ongoing support with Orthotics Department.</p>	<p>The toes on left foot are overlapping. Middle toenail is growing in a V shape and is sharp and difficult to cut.</p>
<p>Moving and handling: Building work is underway on new downstairs extension (bedroom and bathroom), which will help with moving and handling (no stairs to climb) and allow better facilities for short break support.</p> <p>Builder has recently been changed and progress is now being made.</p>	<p>Extension work has been fraught with problems and delays.</p> <p>Home hoist has been playing up. A sling assessment is required when the hoist is functional (OT aware).</p> <p>Our family have never had moving and handling training. Transferring in and out of the car is becoming more challenging. This needs consideration when Motability vehicle is changed. Car seat will soon need adjusting.</p>
<p>Short break support: Current home overnight short breaks service very helpful. The staff are really fantastic and allow Mum to catch up on some much needed sleep.</p> <p>Assessment has been made for contract care (24 nights away from home a year) but no family yet identified.</p> <p>Refer to Children's Hospice for short breaks support.</p>	<p>Three-hour home short breaks in daytime don't allow sufficient time to do anything really meaningful with sister, Lily.</p> <p>Hannah's sleep is easily disturbed at night. She does not always settle back to sleep if disturbed by overnight carers' checks. She is always best left to sleep and only disturbed when absolutely necessary – i.e. when responding to alarm, coughing or settling Hannah if distressed.</p> <p>Still waiting to find a family for 'out of home' short breaks on a regular basis for the next few years.</p>
<p>ENT (Ear, nose and throat):</p>	<p>Sleep apnoea continues. Date set for ENT review.</p>
<p>Dental support: Hannah goes to the family dentist.</p>	<p>H hates having her teeth brushed. We need to find the best way to protect her teeth.</p>
<p>Support at school: Support at school is absolutely brilliant. Teaching assistant fabulous.</p>	<p>It is difficult for Mum to work, due to taking H to school after late wake up on many mornings. There is no 'back-up plan' in place for days off school due to ill health, other than grandparents if they are free. A long-term solution would be useful.</p>
<p>Cleaning: Cleaning helps create time for the family.</p>	<p>It would be great if short breaks service could help with small tasks to support life at home – e.g. ironing.</p>
<p>Leisure/holidays: Enjoying all opportunities to socialise as a family and we love going away on holiday.</p> <p>H loves being entertained. She enjoys going out in her buggy on dog walks, playing with Stickle Bricks and swinging on her swing.</p> <p>H has a keen sense of humour and fun.</p>	<p>We would like to have a holiday away with friends, but due to high support needs we have not found a way to make this possible.</p> <p>'Ad hoc' babysitting for both girls is difficult to organise. We rely heavily on grandparents. This will get more difficult in the future. This excludes us from some of the social activities we would like to join in with.</p> <p>Finding leisure activities that we can take part in as a family can prove very challenging. There are probably leisure facilities that we do not know about. Any help or ideas would be welcomed.</p> <p>Finding leisure activities to help H develop, learn and keep her body and mind active is challenging, especially in the school holidays.</p>
<p>Communication: H can communicate, if she is spoken to clearly, slowly, face to face, and given time to process questions or instructions (please see and use communication chart). The spoken word can be successfully backed up with the use of signing, pictures and Makaton symbols.</p>	<p>Ensuring H is receiving the correct help and support to assist communication and learning. It would be useful to explore if there are any further communication aids that could be used at home.</p> <p>H sometimes grabs and pulls and this can sometimes hurt those looking after her. How do we manage this safely and understand what H is trying to tell us?</p>

5. ONE-PAGE PROFILES

A one-page profile is a summary of important information; describing what really matters to the child/young person and how to support them well. This is built up using all the information gathered with the child/family using person-centred tools and conversations such as 'important to/for,' 'working not working' and 'relationship circles'. Additional tools may also provide useful information, such as 'If I could I would' and 'communication charts'.

It is helpful to attach a photograph of the child to make the profile more personal. This should be quick and easy to read. It can be created as artistically as necessary to make it unique and to have the visual impact required. The key information will generally be:

- child's name and also what they like to be called
- date of birth
- people who are important to the child/young person
- what people have said they like and admire about the child/young person
- their hobbies and interests
- what the child likes and does not like
- how best to communicate with the child/young person if required
- a brief summary of their care and support – describing what good care looks like.

This information gathered and presented can be adapted as required to meet each individual's needs. Other details can be added if required, such as contact details, NHS number, etc.

We own the information about Hannah and our family and have been empowered to use it.
We can update the information ourselves. (Rachel Tyler)

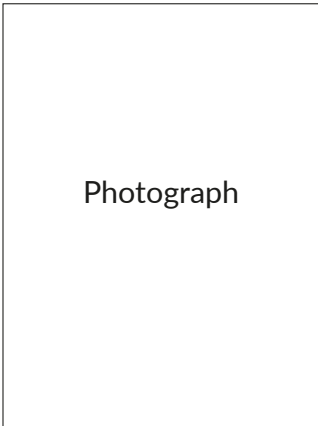
Example: One-page profile template

One-page profile

My name

I like to be known as

My birthday



Important people to me:

What people like and admire about me:

My hobbies and interests. I enjoy:

I like:

I do not like:

Communicating with me:

My care and support needs:

Hannah's one-page profile

My name	Hannah	Photograph
I like to be known as	Han	
My birthday	12 March 2003	
Important people to me: Mum, Dad, Sister Lily, Granny and Grandad, Barney our dog. Teaching assistant Janet, overnight short break carers (Ruth)		
What people like and admire about me: My relationship with dad, mum, sister and family My personality and smile to melt your heart My welcoming nature – a delight to be around School wouldn't be school without me! I enrich everyone's lives I have a strong personality (and will be a strong woman!) I am very affectionate with a wicked sense of humour!	I like: Routine, predictability and familiar adults Being at home with my family and friends Quiet time on my own Stimulating activities at school and home Being able to make choices Being given some independence	
My hobbies and interests. I enjoy: Playing with Stickle Bricks Looking at books and listening to stories Going on dog walks in my buggy Swinging on my swing seat in the garden	I do not like: Anything that is unexpected or unfamiliar To be woken from sleep at any time day or night, as this can affect my breathing	
When talking to me, please: Make face contact and speak slowly, clearly and in short sentences Give me at least 10 seconds to process what you have said Do not keep repeating sentences I understand Makaton and use visual symbols such as picture/photo cards If you would like me to do something, say 'Hannah, do it' or 'It's time for...(bed, tea, etc.)'		
My care and support needs: If woken from sleep, day or night, I may have a 'floppy episode' and will need oxygen and my CPAP (continuous positive airway pressure). I have oxygen at night with an O2 saturation monitor. I use a salbutamol inhaler when I need help with breathing or have a cough. I have visual and hearing difficulties. I have glasses but do not like wearing them. I use a buggy and walking frame to get around. I can also walk holding someone's hands. I have a tracking hoist at home. I wear orthotic boots/splints. I have a special sitting chair to help support me at the table at home/school. I have a special car seat. I wear a supportive hip brace at night. I have a special up/down bed and adapted bathroom. I have specialist ENT, neurology, respiratory and orthopaedic support.		

OTHER PERSON-CENTRED TOOLS

There are a number of other useful person-centred tools or conversations which can help to support those receiving palliative care.

Each child and family is a unique individual. Person-centred tools and conversations can be used on 'pick and mix' basis, depending on a child and family's own situation. A handful of these tools are included in this guide, with examples to illustrate how they have been used in practice.

Person-centred approaches provide easy and practical ways to support staff and families and can also be used to think about their many roles in life, at home, school, work or in care settings.

- If I could I would...
- Communication charts
- What I want and do not want now and in the future – my hopes and fears
- My history...and my important memories
- Good day, bad day.

6. IF I COULD I WOULD (THE DREAM TOOL)

This conversation gives an opportunity for any individual or family to think about things they really want to achieve in their life – things they want to do or see, people they want to spend time with or places they want to visit. It may be things a family wants to do before their child dies. This conversation can help to assess an individual or family's view of their situation and how they are coping. This forms an important aspect of psychological, spiritual and social support in palliative care and helps to maintain hope.

This conversation should be framed carefully around each individual/child/family and what they would like to achieve or what they want their life to look like. It may be that they have had broken sleep for months due to caring for a very ill child and would like to try to get a few peaceful nights' sleep each week. For those who have become isolated through ill-health or disability, it might mean getting out occasionally with friends or as a family. It may be wishing for a holiday if they are unable to get away due to circumstances. It may just be seeing their child maintaining a hobby or interest that makes them happy, such as swimming or riding for the disabled.

Example: Sherelle wrote her first 'If I could I would' for her daughter, Aria, aged almost three years. Good action planning meant these goals were achieved and new goals written and reviewed regularly. 'The dream conversation "If I could I would" gave us a chance to write down and work towards clear goals that we believed we could achieve' (Sherelle Ramus).

If I could I would...

be at home to celebrate Christmas for the first time (not in hospital)

stay well and keep out of hospital

find ways to help others understand my communication better

find better ways of getting around independently

go to church every week with Mummy and Daddy

go out more with my family and friends and visit my family in London

find better ways to make my eczema more comfortable.

7. COMMUNICATION CHARTS

These charts are generally used to help children and young people who use non-verbal communication, such as behaviours, facial expressions and actions, to communicate. Understanding what a child is saying is a fundamental part of enabling and empowering them. It also ensures services are able to give effective support, especially those working closely with a child. Ask the family or carer to describe the different ways in which their child communicates, their facial expressions and behaviours and what they believe it means. Record how they respond and what should be done. This can help to identify pain/fear or discomfort and plan the necessary care/support required by the child.

This makes us and others really consider things from Hannah's perspective. (Rachel Tyler)

Where/when?	What happens?	We think it means...	And we should... (describe what you do)

Example: Hannah's communication chart.

Where/ when?	When H does this	We think it means...	And we should...
Anywhere or anytime	I do not appear to respond to what you are saying.	I am taking time to process and understand what you are saying.	<p>When you speak to me or ask me questions, please make sure that you face me. Talk slowly, clearly and in short sentences to give me a better chance of understanding what you are saying. Please give me as many visual clues as you can. Use signing, pictures, Makaton symbols and show me objects.</p> <p>Please do not keep repeating what you are saying without a break. Say things once and allow me about 10 seconds' processing time. If you repeat things straight away, I have to start processing all over again!</p> <p>Please keep using the same words and sentences. I am very familiar with some sentences such as 'It's time for...' – e.g. 'It's time for bed', 'It's time for a bath', 'It's time for school'. If you want to encourage me to do something, say, 'Hannah, do it.'</p> <p>If you are going to do something to or with me, please tell me what you are going to do before you do it. Give me time to take in what you have said.</p> <p>I have some visual and hearing impairment and cannot always hear and see things clearly. I have glasses but don't like them on my face!</p>
Anytime or anywhere	I give you a Makaton symbol or a picture.	I would like that particular object.	Please give me the object I have requested.

Where/ when?	When H does this	We think it means...	And we should...
Anywhere or anytime	I pinch you, pull your clothes or hair.	I may be <ul style="list-style-type: none"> • tired • feeling crowded • frustrated • in discomfort • bored or have lost interest. 	Move back a bit and let me have a bit of space. Sometimes I need 5–10 minutes quietly to myself. Please stay nearby so that you can see that I am safe but don't sit right next to me.
After my bath in the evening	I pinch you or pull at you, at your clothes or hair.	It is probably because I am tired and it is 'time for bed'.	If it is before 6pm, please entertain me and keep me awake. If it is between 6 and 7pm you can get me ready for bed. My bedtime is 7pm if I can stay awake long enough.
At bedtime	I start shouting.	I may need the toilet or need changing. I may need some reassurance.	Please change me if necessary. Stay calm. Give me some quiet reassurance. Put on my coloured light, on the low setting.
Anytime	I look at a drink you are offering me. I push a drink away quite quickly.	It often means that I may like a drink. I don't want a drink.	Wait patiently to see if I want a drink. Don't rush me. Offer me a choice of drinks please. Use words and Makaton symbols for milk, juice or water. Wait for me to choose which one, give me time to think. Be prepared for me to push the drink away if I do not want it. Please hold the cup for me. Be prepared, I may knock it out of your hand. I think it's funny if you get wet!
Anytime or anywhere	I put my head down so that you can't see my face.	I may be crying as I am in pain. Or I am upset because: <ul style="list-style-type: none"> • you have taken something away from me that I want • there is loud noise that I don't like • someone else is upset/ crying. 	Please sit me on your knee and give me a cuddle and reassure me.
Around mealtimes	I shuffle to my chair at the table and try to sit in it.	I am hungry...or thirsty.	Please get my lunch or tea ready!
Mealtimes	I push my plate or bowl away.	I am not ready to eat. The food is too hot for me.	Remove the food/bowl/plate or be ready to catch my bowl in case I decide to throw it! Please also make sure that the chair next to me is out of my reach as I like to push it over! Please don't crowd me at the table – I am quite happy to eat by myself.
When playing anytime	I throw my toys.	I don't want to play with them anymore.	Let me play with one thing at a time. Give me time and my own space. When I am ready, I will seek you out and might want to sit on your knee.

Example: Sherelle wrote this communication chart for her daughter, Aria, to take with her on first day at school.

When this happens	We think it means	We need you to do this	Medication Please follow my medicine chart
When I'm sitting down or lying down I keep trying to pull myself up.	I want to get up. I want to stand on my feet.	Help me up on to my feet. It's better if you put me in my support shoes to do this.	Glycopyrronium Bromide (1mg in 5mls) (5mls before feed) (to reduce my saliva) Gaviscon (dissolve ½ sachet in each feed) (to reduce tummy acid) Chlorphenamine (4mg tablet) give me ¼ tablet dissolved in 3mls water (for allergic reactions) Calpol (120mg in 5mls sugar-free) give 8mls or Nurofen (100mg in 5mls sugar-free) give 5mls (to help me with pain) Buccal Midazolam 5mg in ready loaded syringe (please follow my seizure emergency care plan) Melatonin (1mg in 1ml) give me 2mls PRN (to help me sleep at night)
I flap my hands, start crying. I puff up my face/cheeks.	I am trying to go to the toilet. I'm probably constipated.	Help me by giving me something to push my feet against. When I'm lying on my back and I start pushing, you can gently push my knees up towards my chest (please don't push too hard).	
I keep crying and appear frustrated.	1. I'm tired. 2. I'm struggling to go to the toilet. 3. I want to move from this chair or position. 4. I am in pain. 5. I feel unwell. 6. I may be de-saturating and need oxygen.	1. Help me to get comfortable, play some music. 2. Help me by giving me something to push my feet against to help me go to the toilet. I take 10 mls Lactulose (3.35g per 5ml) am/pm. 3. Move me to a different position or cuddle me. 4. Check my temperature and give sugar-free pain relief prescribed on medicine chart. 5. Check my temperature and give sugar-free medication to reduce my temperature as prescribed on medicine chart. 6. Check my O2 saturation level, give me oxygen 0.05–0.1 litres from portable cylinder until I settle.	Eczema Creams (See Medicine Chart) Hydromol and Aveeno (<i>used daily on my face and body</i>) Dermovate steroid cream and Protopic cream (<i>only if my eczema flares up</i>) Things that calm me I love my music. I also like singing and cuddles. Please Remember If I am ill I sometimes desaturate during the day. Check my oxygen (O ₂) using my saturation monitor. If below 92% you will need to connect me to a portable O ₂ cylinder at 0.05-0.1 litres. Every night I have O ₂ via nasal cannulae from my oxygen concentrator 0.05-0.1 litres.

When this happens	We think it means	We need you to do this	Medication Please follow my medicine chart
<ul style="list-style-type: none"> • I keep rolling my head. • I am unsettled. • My neck is pink with lots of bumps. • Constant head and neck turning. 	<ol style="list-style-type: none"> 1. I'm tired. 2. My body is itching (eczema). 3. I am having an allergic reaction. 	<ol style="list-style-type: none"> 1. Help me to get comfortable. 2. Place eczema cream on my body & spray on my head. Put on scratch mittens so I don't hurt myself. 3. Give me Chlorphenamine ¼ of a 4mg tablet (dissolve ¼ tablet in 3 mls water) & put down my gastrostomy mini button with 10 mls flush (follow medicine chart). 	<p>WARNING: I am on a strict Ketogenic Diet. I do not take sugar/carbohydrates. Please DO NOT give me anything other than the food my mum provides. Mum checks ketone levels weekly using a monitor.</p> <p>Solids (Ketogenic Diet)</p> <p>If I eat all my food I only need ½ my milk. If I do not eat you will need to carefully judge how much milk to give me.</p>
<ul style="list-style-type: none"> • I look vacant and non-responsive. • I am lip smacking. • Convulsions. 	<p>I am having a seizure.</p>	<p>Please follow my emergency care plan which contains seizure care instructions.</p>	<p>Milk (Ketogenic Diet) via Gastrostomy using my Homeward feeding pump</p> <p>Pump settings: Dose=155 & Rate=310</p> <p>Gravity feed when I am well=100mls milk then make up to 175mls by adding water.</p>

8. WHAT I WANT AND DO NOT WANT NOW AND IN THE FUTURE – MY HOPES AND FEARS

This conversation is really useful for planning ahead and thinking about what an individual, child, young person and/or their family would love to achieve or to happen in the future. What would they like to happen to them if they had a choice? This may be who they want to care for them. It may be where they want to be cared for now and in the future, especially at end of life. It involves discussing what the child/family would like to avoid happening. This is a great conversation and particularly relevant during advance care planning discussions or during the transition of a young person with life-threatening illness who is reaching the age of 18 and moving into adulthood. It is a simple tool to use.





First ask the child or family what their hopes are for the future, Listen and write down their words.



Then ask about their fears or concerns for the future. This is a great way to find out if future hopes seem realistic. Ensure that children and families are made aware of all the options available to them so that they can identify achievable goals or outcomes.

This conversation gave us opportunity to plan ahead and, at any one point in time, we would think about what was important to us now and in the future. We were able to express our hopes and our fears. (Sherelle Ramus)

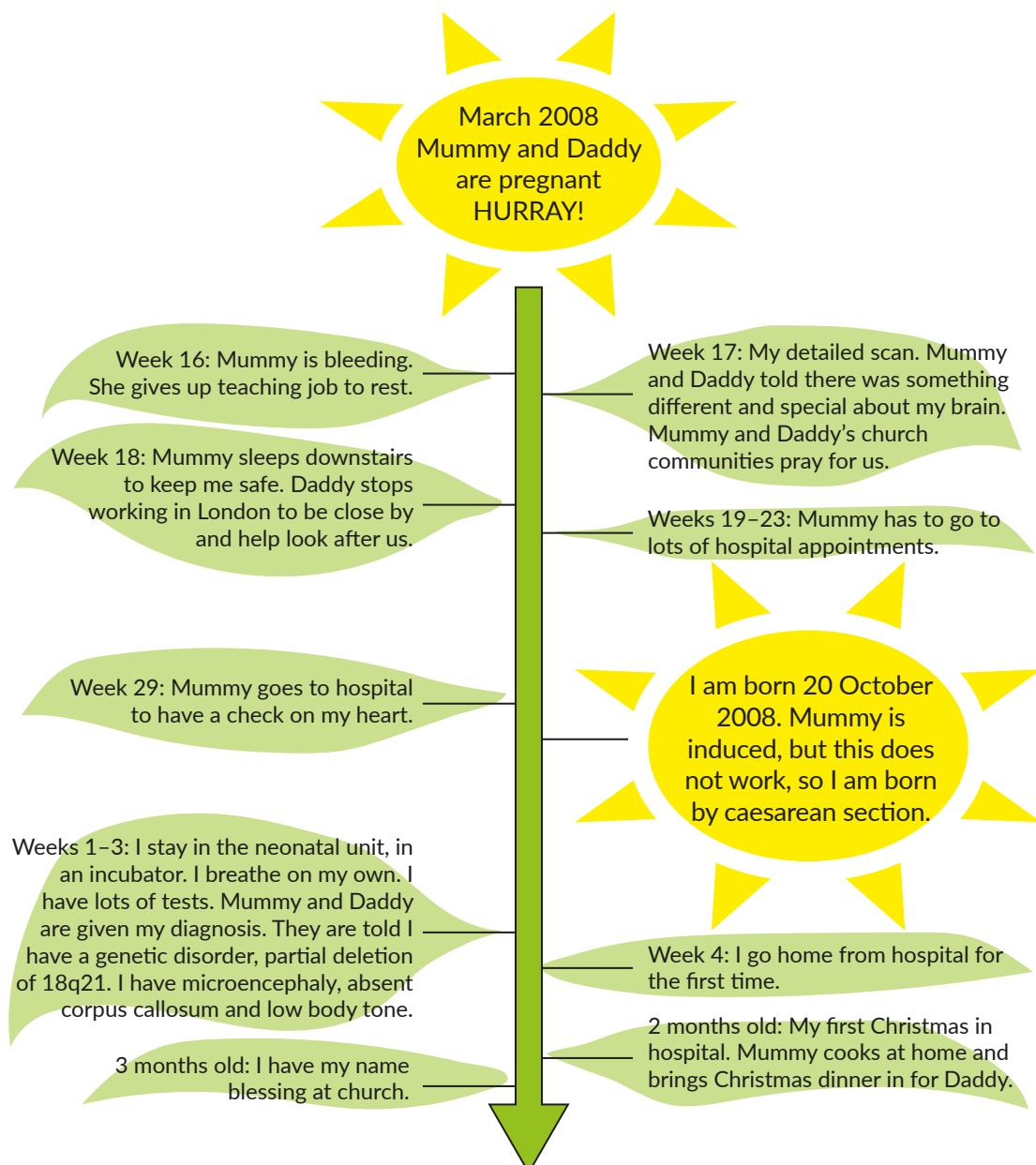
Example: At the end of her treatment for cancer, Emma, who was 16 years of age, described what she was planning now and in the future – she discussed her hopes and fears.

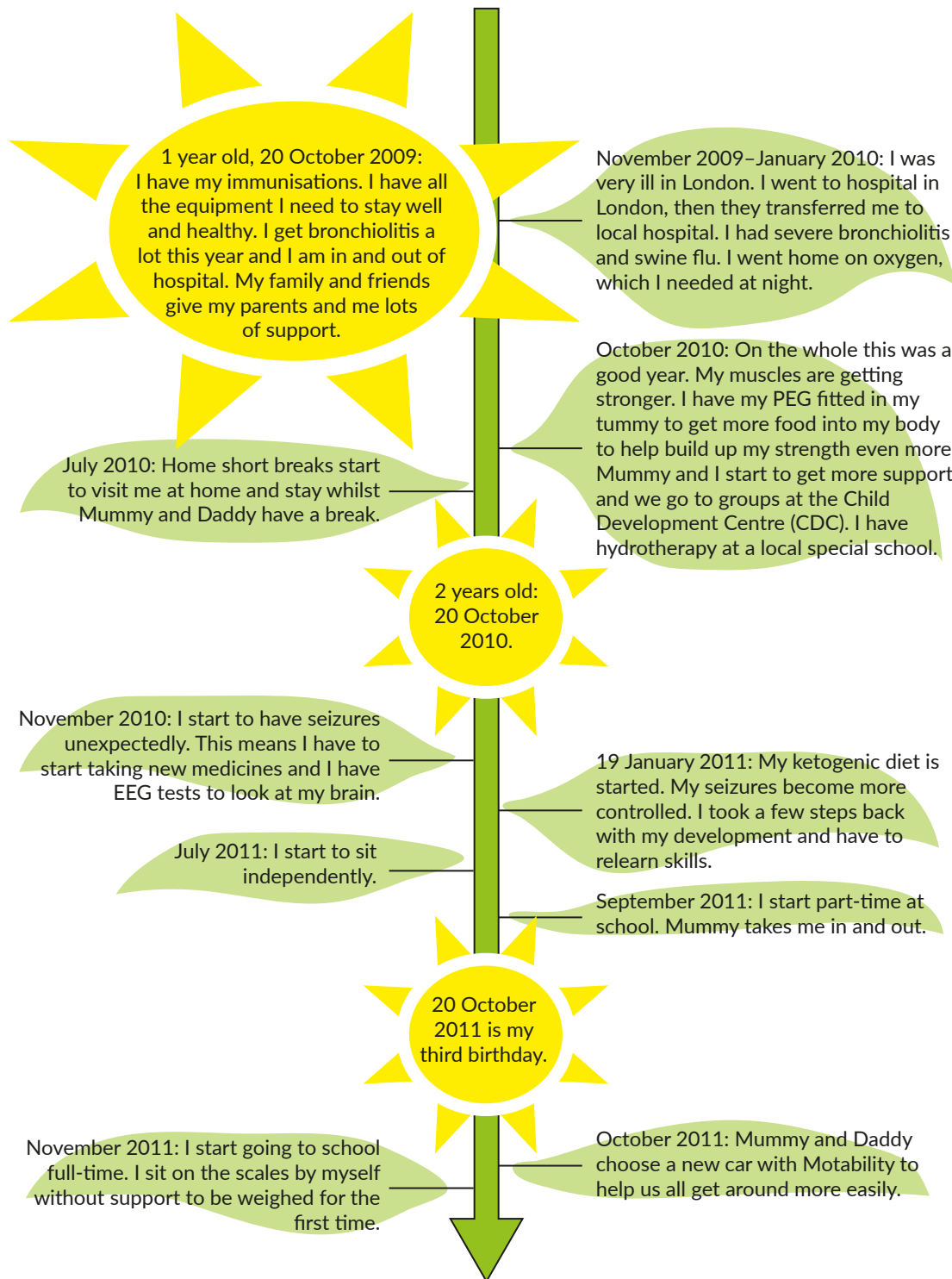
 Hopes	 Fears
<p>No more treatment (I can't remember what life was like before treatment).</p> <p>Not to wear my wig anymore. I would like help to find a new hairstyle that works for me.</p> <p>That I stop feeling tired and worn out all the time.</p> <p>To feel more confident in myself.</p> <p>To get back to school and catch up with school work and take my mocks and GCSEs in science, maths, English, health studies and social care.</p> <p>Go to sixth form college to study childcare.</p>	<p>I am scared about finishing treatment. This has been my life for the last two years – what will happen next? Cancer could come back.</p> <p>Taking my wig off. My hair has grown back and feels different and I don't really like it.</p> <p>Tiredness carrying on.</p> <p>Talking to my mum about how I feel – if I am feeling down or upset, I know it worries her.</p> <p>I won't make it to school as much as I need to, and may not pass my exams.</p>

9. MY HISTORY...AND MY IMPORTANT MEMORIES

This is a way of recording significant or special events that have happened in a person's life. It is a way of recording treasured memories. It can save families repeating information many times to different services. This history may contain details of health, education, social and leisure events. Building a record of treasured events and memories is valuable for families with a child receiving palliative care and also for families receiving bereavement support. There are many other creative ways to record memories – for example, on posters, on film or in photograph albums, in a journal, in a memory box, or by making hand- and footprints.


Example: Sherelle wrote this history and memories for her daughter, Aria, for family and services to read, along with a detailed relationship circle. 'This is useful because we don't have to repeat history again and again – it is written down for anyone to read' (Sherelle Ramus).








10. GOOD DAY/BAD DAY



This is another conversation that helps to gather unique information and can be used to identify things that are important to and important for a person. All of us have good days and bad days. It can be helpful to listen to what makes a really good day for a child and/or family and what happens when bad days occur.

 Discuss what makes a good day for the child/family. Is there anything you or others could do to help good days happen more often?

 Now think about what happens on a bad day. Is there anything that you or others could do to prevent bad days happening, or make them happen less often?

 Good day	 Bad day
What I/we want to change...	

Example: Good day/bad day for James written with the care team and James during a short break at a children's hospice.

 Good day	 Bad day
<ul style="list-style-type: none"> • I like to be involved and in the middle of any activity, especially with my friends or other young people, particularly those my own age. • Being spoken to and able to make choices. • Taking chill-out time when I get tired and need a rest. • Please look at my communication chart to find out the best ways to talk to me and understand what I am saying to you. 	<ul style="list-style-type: none"> • Being 'parked' somewhere in my wheelchair. • Not involved, being left on my own without anyone or anything to do.
<ul style="list-style-type: none"> • Feeling well so I can enjoy the day and activities planned for me. • Comfortable and free from pain – please use my communication chart to understand how I tell you that I am uncomfortable or in pain. Please use my care plan and medication chart to help manage my pain. 	<ul style="list-style-type: none"> • Feeling poorly. • Being uncomfortable or in pain.
<ul style="list-style-type: none"> • Able to enjoy sensory activities and other pastimes that I enjoy such as listening to music, watching music videos and watching TV (especially the soaps). 	<ul style="list-style-type: none"> • Being left without any sensory activities to enjoy.

ACKNOWLEDGEMENTS

1. AUTHORS

Rebecca Riley (RGN, RSCN, District Nurse, MA, PG CERT in personal and business coaching) has worked in a number of clinical nurse specialist roles including that of Cystic Fibrosis Nurse Specialist, Macmillan Nurse and manager of a children's cancer unit, and as Lead Officer of a children's hospice. In 2008 she established a small company offering organisational development (OD) support, training and coaching services. Becca has a special interest in working with children and young people with long-term conditions and complex health care needs, their families and the services that support them. Becca has coached children, young people and families living with long-term illness to help them with decision making, to deal with the changes they face in their lives and to empower them, putting them in the driving seat. She uses a wide range of approaches to support her work, particularly those based in person-centred practice (PCP). Becca has been Practitioner Health Lecturer in Children's Palliative Care at the University of Nottingham; she is a Specialist Advisor for Care Quality Commission (CQC) in end-of-life care and a Clinical Associate for Gold Standards Framework (GSF). She is an active member of the East Midlands Children's and Young People's Palliative Care Network (EMCYPPCN) and a member of the faculty at East Midlands Leadership Academy.

Rachel Tyler has been trained in using person-centred planning (PCP) and has helped develop this guidance from a parental perspective. Rachel wears many hats. She once described herself as a Mum, Wife, Expert parent-carer, Lawyer, Household administrator and manager! She says: 'I attended a two-day person-centred planning programme with my twin daughters about six years ago. We were introduced to a range of person-centred planning tools and conversations, alongside other families and some of the services that supported our family. We have since had experience of using many of these tools in our daily lives. Some of the examples I have included demonstrate the useful person-centred conversations we have had and the records we have made, and explain why person-centred planning has helped us. I hope they help to illustrate how person-centred thinking and planning can build up a more complete picture of a child or family in the world in which they live and belong and where care and support will take place on a daily basis.'

Sherelle Ramus was trained in person-centred planning (PCP) and started to use some of these approaches when her eldest daughter, Aria, was three years old and about to start attending special school. Aria was born with a complex genetic disorder and as a baby her health was unstable and management was challenging. 'PCP increased our confidence to talk to the many different services we received support from and allowed us to take more

ownership as a family. PCP is now common language in many different services and as a family we have shared person-centred information to support our daughter at school and with home short breaks carers. The information we recorded also supported us through adoption processes. We saved all this information on our computer and can easily update it ourselves as and when needed. We have had some useful and challenging conversations and using person-centred approaches enabled us to take time to reflect and think through many challenges in a different way, often finding creative solutions. We hope this guide helps others to do the same.'

2. CONTRIBUTORS AND SUPPORTERS

Dr Lynda Brook, Macmillan Consultant in Paediatric Palliative Care, Alder Hey Specialist Palliative Care team, is a firm believer in person-centred planning (PCP). Her ongoing support and input over a number of years is greatly appreciated to help achieve this written PCP guidance, for children and young people receiving palliative/end-of-life care, their families and the services who support them.

In 2012 **Sacha Langton-Gilks's** son, David (known as DD), died peacefully and happily at home of a brain tumour, aged 16. The local GP's surgery had been through Gold Standards Framework (GSF) training in end-of-life care and provided the family with excellent coordination of care between the hospital and the community care teams. Sacha is a singing teacher, gardener and writer. She is also a Lead Champion for the HeadSmart campaign. Sacha spoke publicly to other parents, at the request of the Brain Tumour Charity, about the process of managing DD's death at home. This was in response to the needs of families in the end-of-life phase, who had said they did not receive information and felt isolated. She has since presented to health professionals at a Gold Standards Framework event and was asked to write her experiences down – hence the publication of this book.

Sarah Everest, NHS Commissioner and Registered Children's Nurse, has supported the development of this guidance and the ongoing person-centred work with families, for which we are very grateful. She says: 'This guide is a really useful and practical tool for families and professionals to use for person-centred planning in their everyday life. Being developed by parent-experts and a health professional with years of experience and a passion for person-centred planning ensures it is a simple and easy-to-use guide. People can feel daunted by new initiatives such as PCP and may think that this is time-consuming and complicated. This guide contains lots of useful tools and examples that can be used regularly in practice to support families and ensure that their child is kept at the centre of integrated care provision. I hope many families and professionals will benefit from the use of this excellent guide and toolkit.'

Together for Short Lives have supported the development of this guidance. Examples in it have been shared at Together for Short Lives national events to support integrated education, health and care (EHC) planning. The charity has a wonderful website, which is extremely helpful. Please follow the link to the TfSL's website to find resources and information to support families and professionals: www.togetherforshortlives.org.uk.

The team at **Gold Standards Framework** has been very supportive of the work to develop this document. We hope this guidance encompasses the ethos of GSF, in promoting person-centred thinking and practice to help promote 'Living well' and 'Dying well'.

Thanks go to **Dr Sue Neilson**, Lecturer, School of Nursing, University of Birmingham, for her support in the development of this guidance and for securing a funded research evaluation of the person-centred toolkit in practice. Sue's research interest in children and young people's (CYP) palliative care has been informed by over 20 years' clinical nursing experience in this field.

We are so very grateful to **Clare Periton**, Chief Executive and **Dr Emily Harrop**, Consultant in Paediatric Palliative Care, both from Helen and Douglas House Hospice, for their contributions to the foreword of the Person-Centred guidance and for their on-going support and encouragement with the development of this resource and in aligning its application to best practice as described in the NICE guidance on End of Life Care for Infants, children and young people with life limiting conditions: Planning and management (NG 61).

BIBLIOGRAPHY

- Department of Health (2008) *Better Care: Better Lives. Improving Outcomes and Experiences for Children, Young People and Their Families Living with Life-Limiting and Life-Threatening Conditions*. London: Department of Health.
- Department of Health (2010) 'End of life care planning with people who have a personal health budget.' Discussion paper produced by the Department of Health's personal health budgets pilot programme and the NHS National End of Life Care programme. London: Department of Health.
- Department of Health (2010a) *Personalisation through Person-Centred Planning*. London: Department of Health.
- National Institute for Health and Care Excellence (NICE) (2016) End of Life care for infants, children and young people with life-limiting conditions: planning and management, NICE guideline. www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-life-limiting-conditions-planning-and-management-1837568722885.
- National Institute for Health and Care Excellence (NICE) (2017) End of life care for infants, children and young people Quality standard [QS160]. www.nice.org.uk/guidance/qs160/history.
- O'Brien, J. and Lovett, H. (1992) 'Finding a Way toward Everyday Lives: The Contribution of Person-Centred Planning.' In J. O'Brien and C.O. O'Brien (eds) *A Little Book about Person-Centred Planning*. Toronto: Inclusion Press.
- Ritchie, P., Sanderson, H., Kilbane, J. and Routledge, M. (2003) *People, Plans and Practicalities: Achieving Change through Person Centred Planning*. Edinburgh: SHS Trust.
- Sanderson, H. (2000) *Person-Centred Planning: Key Features and Approaches*. York: Joseph Rowntree Foundation.
- Sanderson, H. and Lewis, J. (2011) *A Practical Guide to Delivering Personalisation: Person-Centred Practice in Health and Social Care*. London: Jessica Kingsley Publishers.
- The Health Foundation (2014) *Person-Centred Care Made Simple: What Everyone Should Know about Person-Centred Care*. London: The Health Foundation.
- Together for Short Lives (2017) Palliative care definitions. Accessed on 27/06/17 at www.togetherforshortlives.org.uk.
- Wolfensberger, W. (1972) *The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation.

RESOURCES

- Chambers, L. and Taylor, V. (2014) *A Family Companion to the Together for Short Lives Core Care Pathway for Children with Life-limiting and Life-threatening Conditions* (3rd edition). Bristol: Together for Short Lives.
- Helen Sanderson Associates (2010) *Living Well: Thinking and Planning for the End of Your Life*. Stockport: HSA Press.
- Helen Sanderson Associates – Please do visit the Helen Sanderson Associates website where you will find a wide range of useful tools and resources to support person-centred planning: <http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools>
- Sanderson, H. and Taylor, M. (2008) *Celebrating Families: Simple, Practical Ways to Enhance Family Life*. Stockport: HSA Press.
- Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them – families, professionals and services. Do visit the Together for Short Lives website where you will find a comprehensive collection of resources and information: www.togetherforshortlives.org.uk.