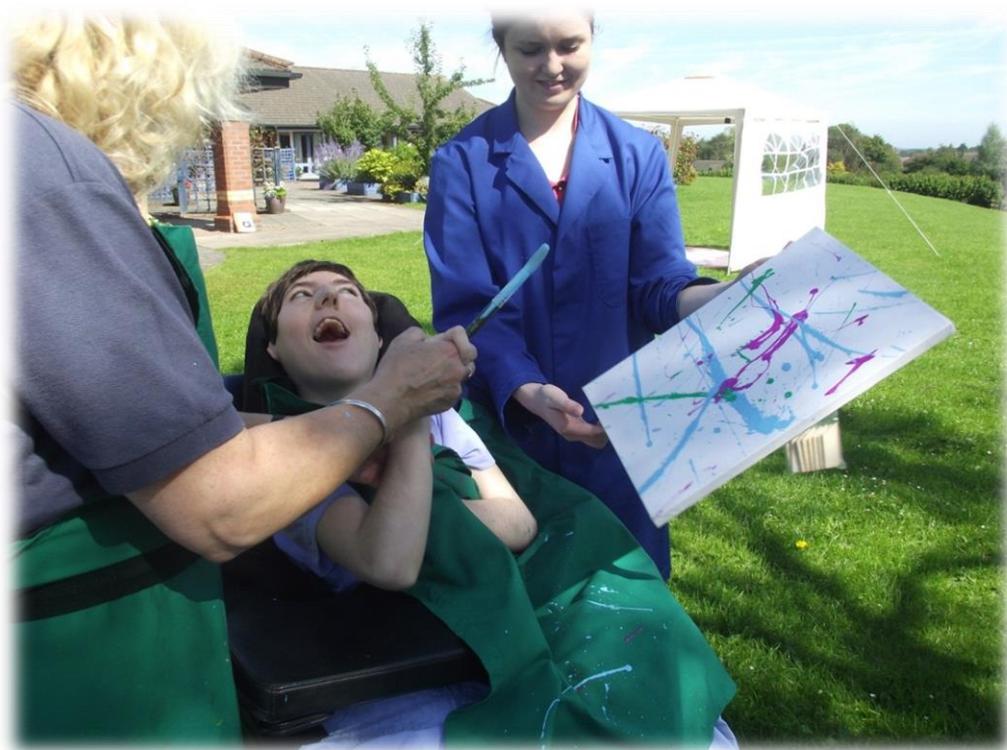


Using Person Centred Approaches and Multi-Agency Liaison to Incorporate Palliative Care Needs in Transition Services:



A guide for key workers and practitioners

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This work was funded by Together for Short Lives, a UK wide charity supporting children, young people and their families living with life-limiting and life-threatening conditions.

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Bangor University, United Kingdom.

The accompanying report and a film about young people's experiences of transition planning in palliative care settings can be viewed at the following link:

<http://www.bangor.ac.uk/so/bridging-the-gap/index.php.en>

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This guide and the six transition planning tools are designed to capture health and social care issues of importance to young people that are commonly missed in transition plans. They are to be used in conjunction with the young person's care plan, overarching transition plan, if appropriate an end of life care plan, and person-centred thinking tools. You can learn about **person-centred thinking tools** at:

www.learningcommunity.us

or at the Helen Sanderson Associates website:

<http://www.helensandersonassociates.co.uk/>

See also the MY QuOL-T – Measure Yourself Quality of Life Tool.

MY QuOL-T is a free web-based tool developed by Dr Nicky Harris at Children's Hospice South West to enable young people and parents to document, describe, and monitor the issues that make the most difference to their own quality of life and, if desired, to share these issues with the professionals involved in their care. You can learn about the MY QuOL-T – Measure Yourself Quality of Life Tool at:

<http://www.my-quality.net/>

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Introduction

Many children and young people with palliative care needs who could benefit from palliative care services remain unrecognised by service providers. In particular young people age 14 to 25 years tell us that their palliative care needs are frequently not picked up or not met when they transition to adult services (Noyes et al 2014). Models of palliative care and the patient groups they serve vary between children's and adult services. Figure 1 shows a composite model of palliative care specifically for young people and young adults with life-limiting and life threatening conditions. Current adult palliative care services will need adapting for young adults with life-limiting and life-threatening conditions to align with this model (ACT 2009).

Figure 1: Composite model showing core elements of continuous holistic palliative care during and after transition from children's to adult services for young people with life-limiting and life-threatening conditions (from Noyes et al 2014).

1	Continuity of health promotion¹, active treatment and holistic palliative care from diagnosis onwards through transition and into adulthood.
2	Continuity of pain and symptom management to ensure that pain and discomfort and other adverse symptoms are kept under control.
3	Continuity of skilled communication and joint decision making inclusive of young people/young adults and their families and carers. Timely and developmentally appropriate and dynamic assessment of mental capacity of young people and young adults in complex decision making.
4	Continuity of family centred care and person-centred support inclusive of the entire family, including siblings of the young person/young adult.
5	Continuity of key working as a core component of family and person centred palliative care for a young person/young adult; helping to negotiate the multiple services that a young person/young adult and their family may need access to.
6	Continuity of condition-specific care planning/care pathways that refer to the purposive and supportive planning with a young person/young adult for the delivery of their care needs both now and in to the future and through transition to adulthood and beyond.
7	Continuity of advance care, transition and post transition planning to ensure that young people/young adults and their families receive equitable access to the holistic support and care they need in a timely manner.
8	Continuity of multi-agency care to ensure that the young person/young adult is placed at the centre of what can be a complex care system including GP, local hospital, community nursing team, hospice, social services, school and higher education, employment and housing services.

9	Continuity of psychological support for both the young person/young adult and for the family.
10	Continuity of short breaks/respite care for the benefit of the young person/young adult and the family.
11	Continuity of end of life care including provision for the young person/young adult to die in their own home, if this is their choice.
12	Continuity of bereavement support for the family during the young person/young adult's illness and following their death.

¹ The concept of health promotion as a function of palliative care is derived from the work of Virginia Bennett (2014)- PhD student at Bangor University supervised by Jane Noyes and Richard Hain.

Together for Short Lives (formerly ACT) have published a Transition Pathway (ACT 2007). Currently available transition guidance and care pathways rely on the ability of the people developing the transition plan to be able to articulate individual needs that would benefit from palliative care. Young people and young adults in the Bridging the Gap study told us that there were important health and social care issues that were frequently missing from transition plans (Noyes et al 2014). Many of these health and social care issues were those that could be met by palliative care and services. This situation urgently needs addressing.

The purpose of this guide is to support key workers and practitioners to identify and integrate palliative care needs that are commonly not included into multi-agency transition care planning for young people age 14-25 years with life-limiting and life-threatening conditions.

Key Worker/Working

The focus of the guidance is on **a key worker or someone performing a key working function:**

- Meeting with the young person and their family to make sure that their palliative care needs are captured, communicated and anticipated in person-centred ways.
- Assisting a young person to think about and communicate their own palliative care needs.
- Liaising with multi-agency professionals on behalf of the young person and family to ensure that their palliative care needs alongside their other needs are acknowledged and met during and after transition.
- Integrating palliative care needs with existing daily care plans into overarching transition plans, and if appropriate end of life care plans.
- Fostering continuity and a family centred approach.

Key Worker Role and Key Working Function

A description of the key worker role and function can be found in Appendix 2. A highly skilled key worker or someone performing a key working role can reduce the complexity of transition planning for families. Figure 2 shows what happens when families manage communication channels in the transition process by themselves, and Figure 3 shows what happens when a skilled key worker or a person performing the key working function manages the process on behalf of the young person and their family.

As a key worker or someone who is key working, you may also wish to use the Living Well guide (2014) which sets out the key person-centred thinking tools to consider using with children with palliative care needs and their families, including end of life planning.

Figure 2: Channels of communication that the young person and their family manage **without** a key worker

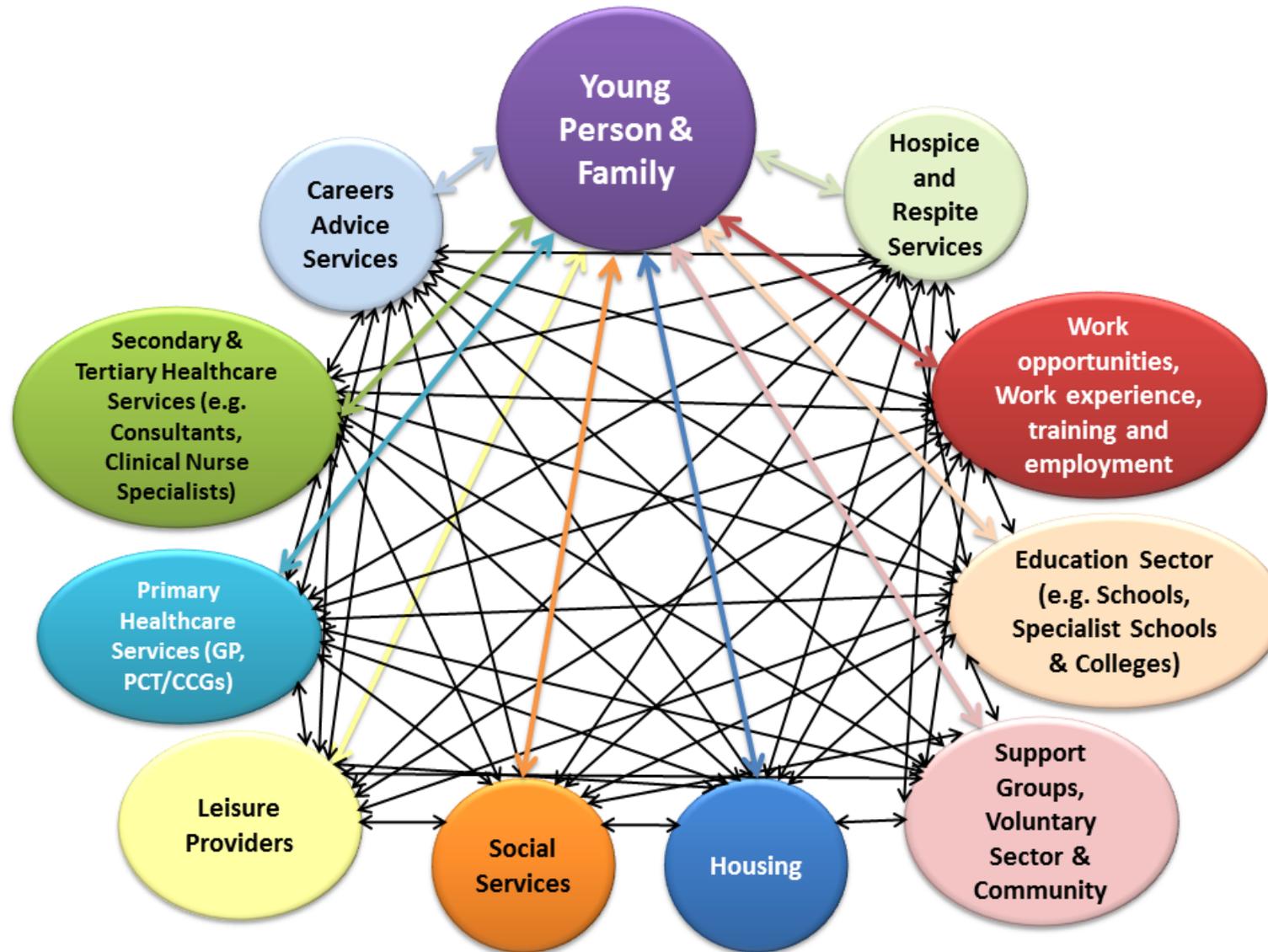
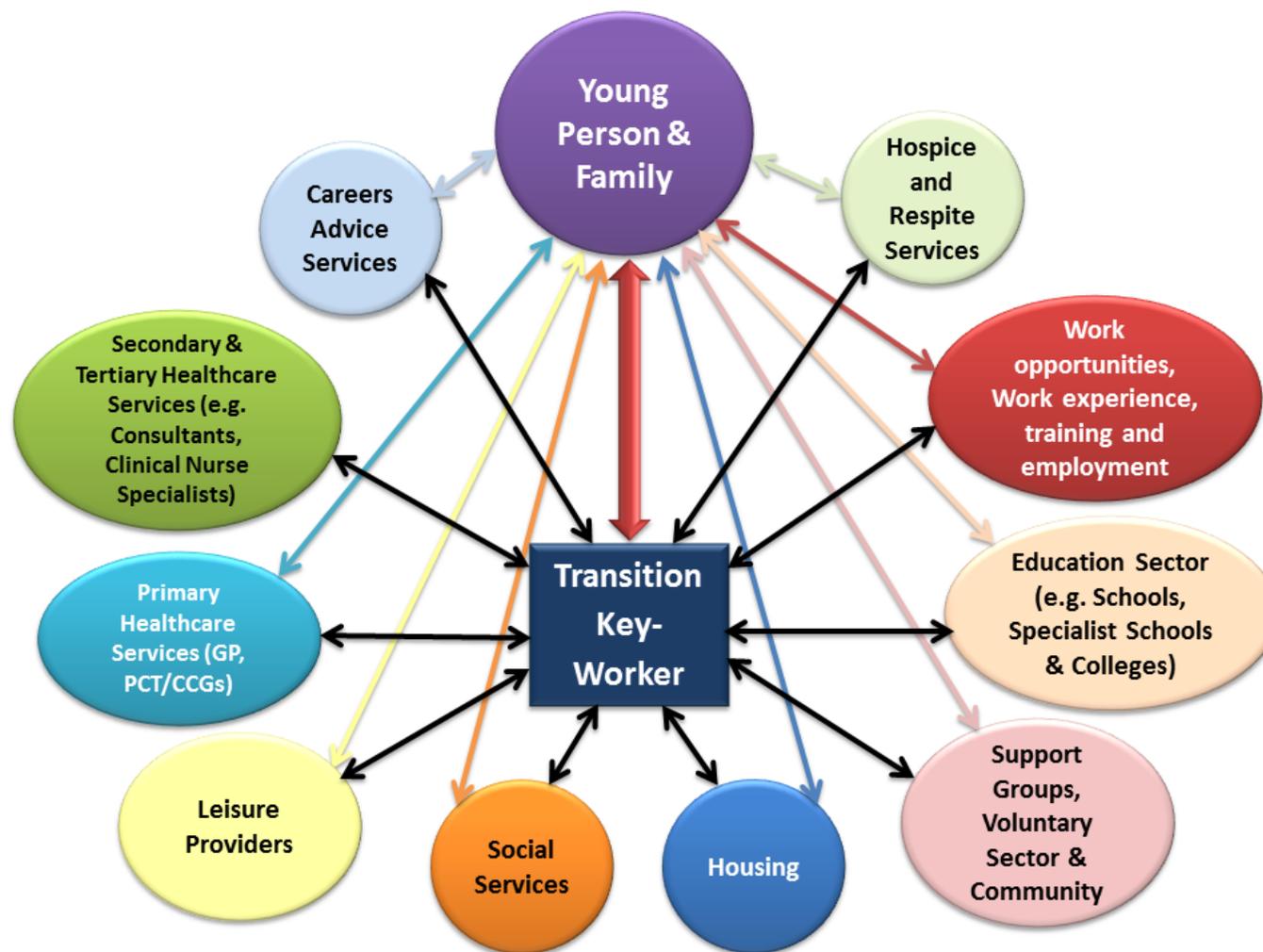


Figure 3: Channels of communication that the young person and their family manage **with a key worker**



To be effective, the key worker or person with the key working function will need:

- Person-centred planning and communication skills
- Condition-specific knowledge in order to anticipate and plan ahead for unexpected and expected exacerbations and fluctuations in palliative care needs
- Good knowledge of and contact with all the professionals and services that the young person has or may come into contact with in children's and adult multi-agency services
- Awareness that the young person and individual multi-agency professionals and services may have existing or may be developing their own transition plans that need to be brought together to incorporate palliative care needs in a coordinated way

Common missing elements of health and social care transition planning with potential palliative care needs

Six key health and social care elements are commonly absent from current transition care plans that may be of relevance to the young person (Noyes et al 2014). Person-centred assessment of these elements could potentially identify needs that may be met by palliative care. The six elements are as follows:

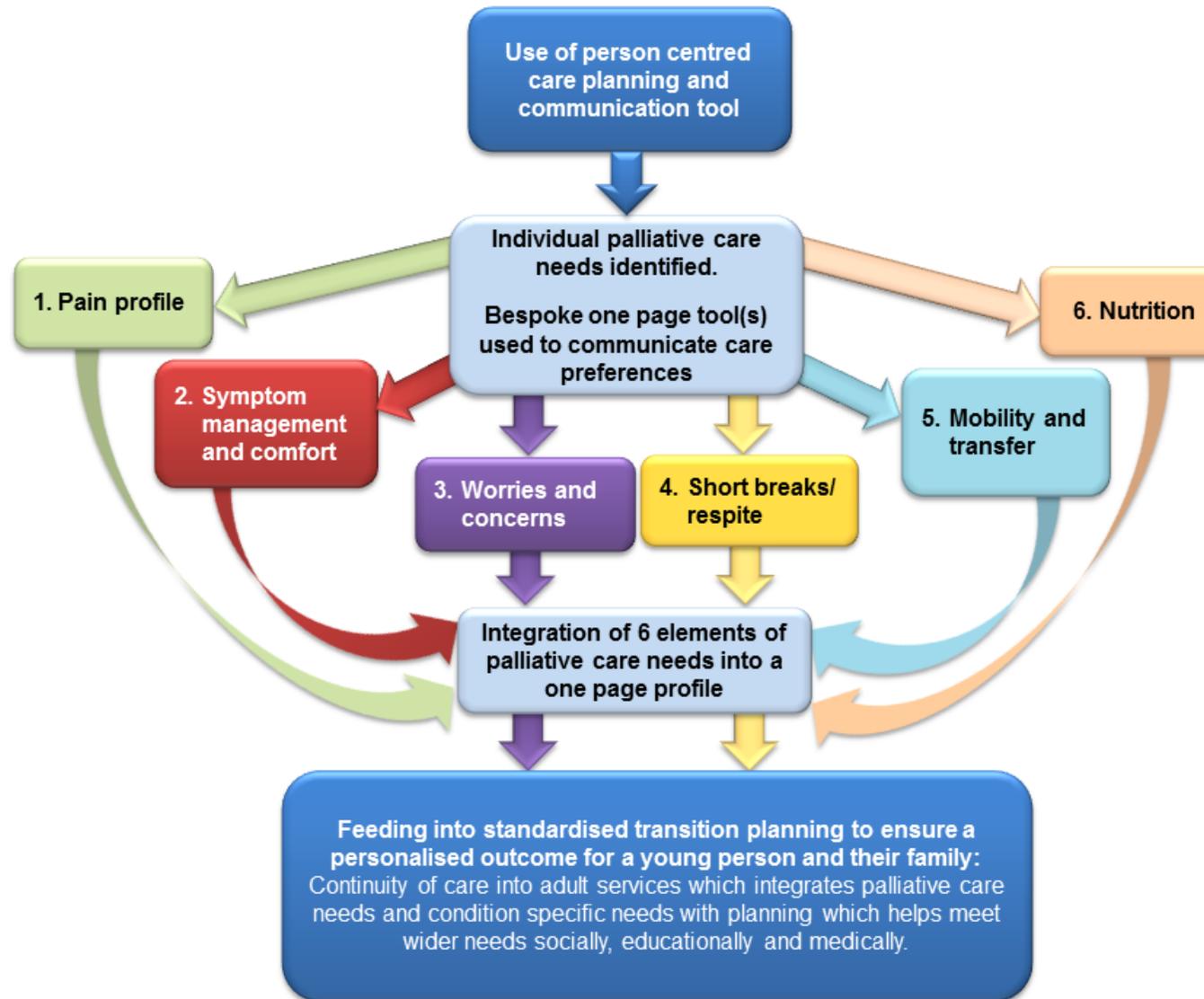
- 1. My pain profile.**
- 2. Managing my symptoms and keeping me comfortable.**
- 3. My worries and concerns and how best to support me and my family.**
- 4. How best to support me with short breaks and respite.**
- 5. What is important for you to know about my mobility and how to support me with transfer?**
- 6. Nutrition, food and drink.**

Figure 4 shows how the 6 key health and social care elements can feed into transition planning.

The person-centred tools for each element can be used with existing care planning documents to identify specific palliative care needs. These tools are accompanied by a transition checklist which focuses practitioner and key worker thinking and action planning around what is available in adult services and what palliative care a young person will or is likely to need in the future.

Young people and their parents may also find it helpful to use the web-based **MY QuOL-T tool** to better understand and communicate their changing palliative care needs over time with professionals.

Figure 4: Six health and social care elements commonly requiring palliative care interventions that are frequently missing from transition care planning



Many young people and professionals also find it challenging to identify and plan for individual symptom management in person-centred ways. The MY QuOL-T tool may help young people and their parents to better describe and communicate symptoms and emotional and behavioural issues. For professionals, we have produced a symptom wheel as an aide memoire covering the broad range of common symptoms in palliative care.

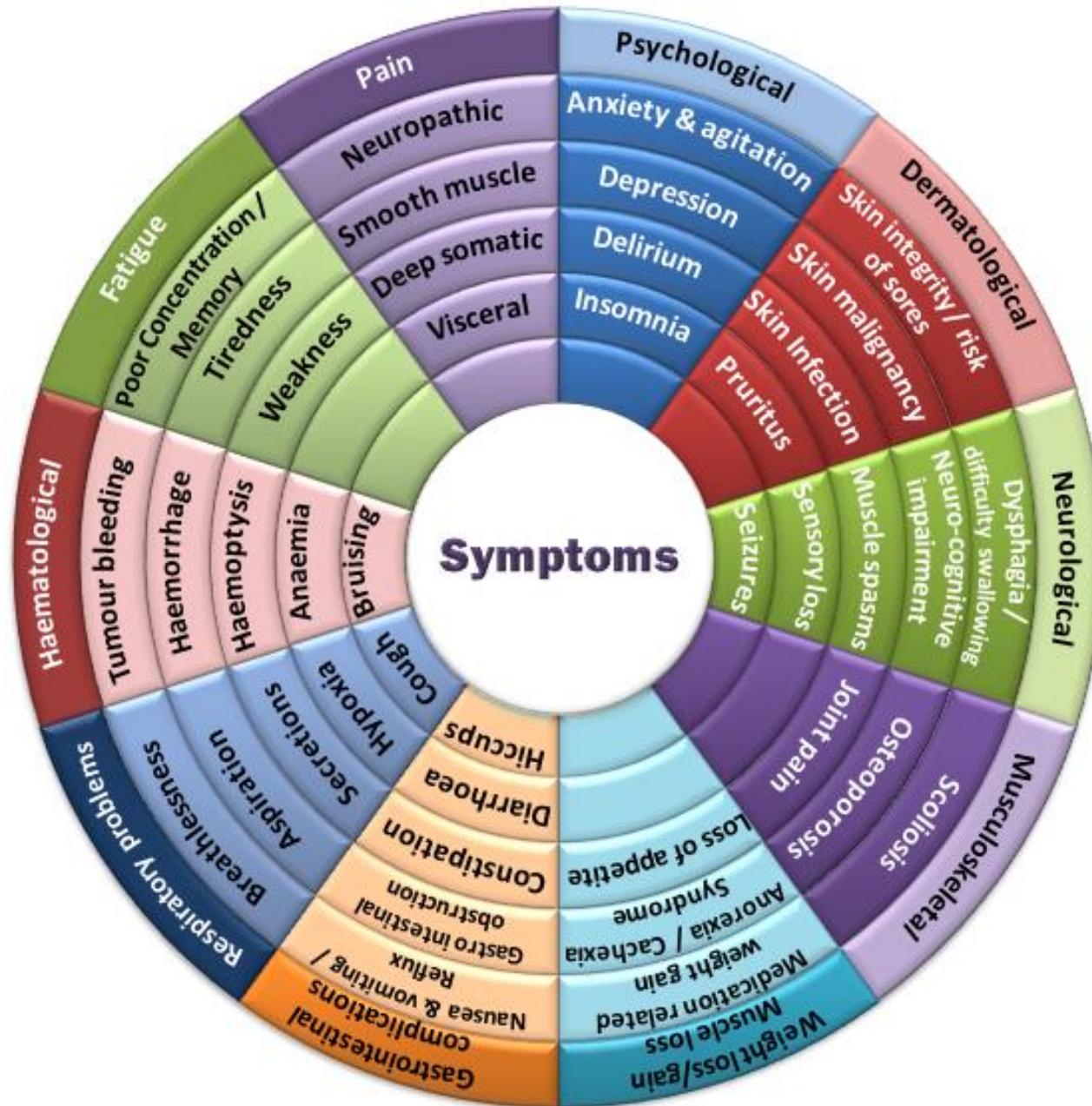
We have produced **a symptom wheel of common symptoms** that may need assessing, anticipating and palliation. The wheel is for use by professionals

(See Figure 5).

When seen in isolation, the symptoms in the wheel can appear very 'medical' in orientation and primarily require support from health, palliative care and hospice services to address.

Palliative care needs add another level of complexity to providing care. **Having unaddressed palliative care needs can restrict a young person's participation in social activities, access to education and employment and independent living, and severely impact on their quality of life.**

Figure 5: Symptom Wheel



Getting started

The aim of transition planning for young people with life-limiting and life-threatening conditions is to include all their holistic needs (education, housing social care etc), and their specific health and palliative care needs.

1. The starting point is always the young person and their family to find out their thoughts and perspectives about their palliative and complex care needs in person-centred ways.
2. Begin by using the young person's existing communication profile with the young person to understand how they communicate; their comprehension and expressive language skills, and how they would like to be communicated with. If they do not have a communication profile – then develop one with the young person.
3. Many young people with life-limiting and life-threatening conditions and parents will not think of their care as 'palliative care'. The young person's care will be provided by a whole range of services, some of which are badged palliative and some which are not.
4. The young person may already have a one page profile, daily care plan and complex needs transition plan, and if appropriate an end of life care plan, that takes account of some or all of their palliative care needs.
5. If the young person does not have an appropriate one page profile or their existing plans are not sufficiently person-centred, or existing plans do not provide the right palliative care information, consider using the six palliative care transition planning tools in this guidance.
6. Young people and parents complain about having multiple assessments and engaging in multiple episodes of care planning with different agencies, and telling the same information time and time again to various professionals. A key worker or someone performing the key working function can help minimise but not remove this duplication. Young people appreciate it when key workers take time to look at

their current plans and only ask for additional updated or relevant information.

7. With the young person's permission, contact the professionals that currently provide support to meet the young person's identified care needs to find out if they have a transition plan or transition pathway in development or in place.
8. Consider how best to integrate all the information, assessments and perspectives (young person, parent, professional) into a person-centred, coordinated and coherent transition action plan that is communicated to all relevant parties.
9. Palliative care needs can rapidly fluctuate and increase both unexpectedly and expectedly. Key workers need to anticipate and be responsive to any changes and update palliative care transition plans accordingly.

Communicating with young people and young adults with life-limiting and life-threatening conditions

The following considerations can be used as prompts to underpin person-centred approaches to communication with young people.

It is critical to recognise that it is not possible to know what it is like to be someone else. We can, however, make sure that our practice as communicators is patient and adaptable.

1. Consider how the young person communicates. This may include **non-verbal means of communication** using Makaton or sign language, pictorial or visual aids or alphabet boards. Make effective use of their communication tools when appropriate to do so. Also **consider language preference** and involve family members and care givers where appropriate who will know the communication needs of a young person and with whom the young person is familiar.
2. Seek to find out whether a young person responds to particular **environmental stimuli such as music, colour, lighting** or the presence of a particular family member, carer or professional. This may be especially pertinent when communicating with a young person with sensory/multi-sensory impairment such as auditory or visual.
3. Ensure **communication is age / developmentally appropriate** and understandable for a young person.
4. Young people will know their condition better than anyone else in terms of its challenges, how it makes them feel and **their main worries and anxieties**.
5. Communicate with a young person at a pace and in an environment which is conducive with effective communication and which does not exacerbate a young person's distress. Avoid busy environments where there is potential for significant distractions, sensory overload and onset of distress resulting from **avoidable misunderstanding**.
6. Whilst a young person may have reached adulthood and be considered an autonomous decision maker, their preference may be to involve family in or delegate aspects of decision

making to family members. Excluding family from this process post 16 or 18 can be both an unnatural shift and detrimental to a young person and their family's sense of well-being and control.

7. **Supporting** a young person to make **joint decisions** is a cornerstone of person-centred communication in palliative care.
8. A family centred approach should underpin communication and decision making with young people that is appreciative of the **context of a young person's family life and wider social network.**
9. Ongoing assessment of what a young person would like and what is important to them is central to transition planning as their views and preferences may evolve and change over time.

Bridging the Gap Palliative Care Planning Toolkit

The six domain person-centred palliative care plan

Check to see if the young person's existing one page profile, care plan, complex transition plan or if appropriate end of life care plan adequately addresses the following six key areas in person-centred ways.

These six areas are:

1. **My pain profile**
2. **Managing my symptoms and keeping me comfortable**
3. **My worries and concerns and how best to support me and my family**
4. **How best to support me with short breaks and respite**
5. **What is important for you to know about my mobility and how to support me with transfer?**
6. **My nutritional needs**

If in doubt use the relevant palliative care planning tools in this guidance.

The 6 key tools are designed to feed into the young person's standard transition care pathway where 'gaps' are evident in meeting their palliative care needs.

The six tools are designed to ask key questions around palliative care needs and they should be used **in conjunction** with the following person-centred planning tools which capture a young person's needs:

- Important to and how best to support
- What's working/Not working
- Communication profile
- Communication chart
- Decision-making
- Good day/Bad day
- Learning Logs

These tools are available at: www.helensandersonassociates.co.uk

The young person and their parents may also find the MY QuOL-T – Measure Yourself Quality of Life Tool useful to share their perspectives with professionals:

<http://www.my-quality.net/>

Key Worker Checklist and Action Plan

A key worker checklist and action plan template can be used to draw together the information from each relevant tool (e.g. Short Breaks / Respite tool), to think about what the young person will need in adult services.

KEY WORKER PALLIATIVE CARE TRANSITION CHECKLIST AND ACTION PLAN	
1. Are the young person's palliative care needs optimally managed now or do they need re-assessment?	
Comments:	
Action:	
2. Are age appropriate evidence-based tools being used to assess and monitor their palliative care needs (e.g. pain assessment tools, MyQuOL_T)?	
Comments:	
Action:	
3. Has the young person and their family been signposted to appropriate self-care and self-help guides/programmes?	
Comments:	
Action:	
4. What aspects of the young person's condition do you need to familiarise yourself with to better understand the nature of their palliative care needs and anticipate future support?	
Comments:	

Action:

5. What are the likely or potential condition-specific palliative care needs as the young person grows older?

Comments:

Action:

6. Are there appropriate adult services to help the young person manage their potentially fluctuating or escalating palliative care needs once they leave children's services?

Comments:

Action:

7. Are adult services aware of any potential palliative care management issues with the young person?

Comments:

Action:

8. Do the adult professionals and services require upskilling and planned orientation during transition and beyond to prepare for taking over management of the young person?

Comments:

Action:

9. Has the young person's palliative care need(s) been considered jointly by appropriate children's and adult services?

Comments:

Action:

10. What is the best way to facilitate smooth transition to the most appropriate adult services for this particular young person?

Comments:

Action:

11. If no appropriate adult service exists or no adult service can flexibly accommodate the young person's needs how is this information going to be proactively fed back to commissioners, the young person and parents?

Comments:

Action:

12. Are there any other alternatives worth considering? E.g. apply for continuing care funding, direct payments, referral outside of region or to private provider?

Comments:

Action:

13. What plans are in place within children's/adult services to support the young person and family in the event of sudden/unpredictable or unforeseen exacerbation or end of life palliative care management needs?

Comments:

Action:

14. How often does the young person's palliative and complex care plan need reassessing and revising to meet changing needs and condition-specific life course?

Comments:

Action:

15. Is planning for 'what if' scenarios sufficient? (e.g. what plans are in place if the young person recovers suddenly from an end of life situation?)

Comments:

Action:

1. My pain profile

This tool is designed to *focus carers and practitioners on the individual experience of pain by a young person, and to find out:*

- *What the challenges of pain experience are for the young person;*
- *What they recognise or suspect to be triggers of sudden pain onset and;*
- *How best they would like to be supported to manage their pain.*

In addition, contact details can be provided of a care provider who is likely to be more familiar with what is common or uncommon in terms of pain presentation for the young person. This tool can increase familiarity with the way in which pain is experienced and perceived by a young person and also reduce potential for avoidably exposing a young person to environments which are likely to trigger or make their pain worse.

See appendix 1 Thomas' profile and Cynog's profile for examples on how a young person's pain management needs can be captured in a person centred way.

1. My pain profile

NAME

DOB:

AGE:

DATE COMPLETED:

Important things I would like you to know about my pain

These are some of the symptoms I often experience alongside my pain

How my pain affects me day to day

These are things you need to be aware of which sometimes trigger my pain ...

What you can do to best support me when I am in pain

This person knows my condition well and how best to support me:

Relationship:

You can contact them using their contact details:

2. Managing my symptoms and keeping me comfortable (also refer to specific tool for pain)

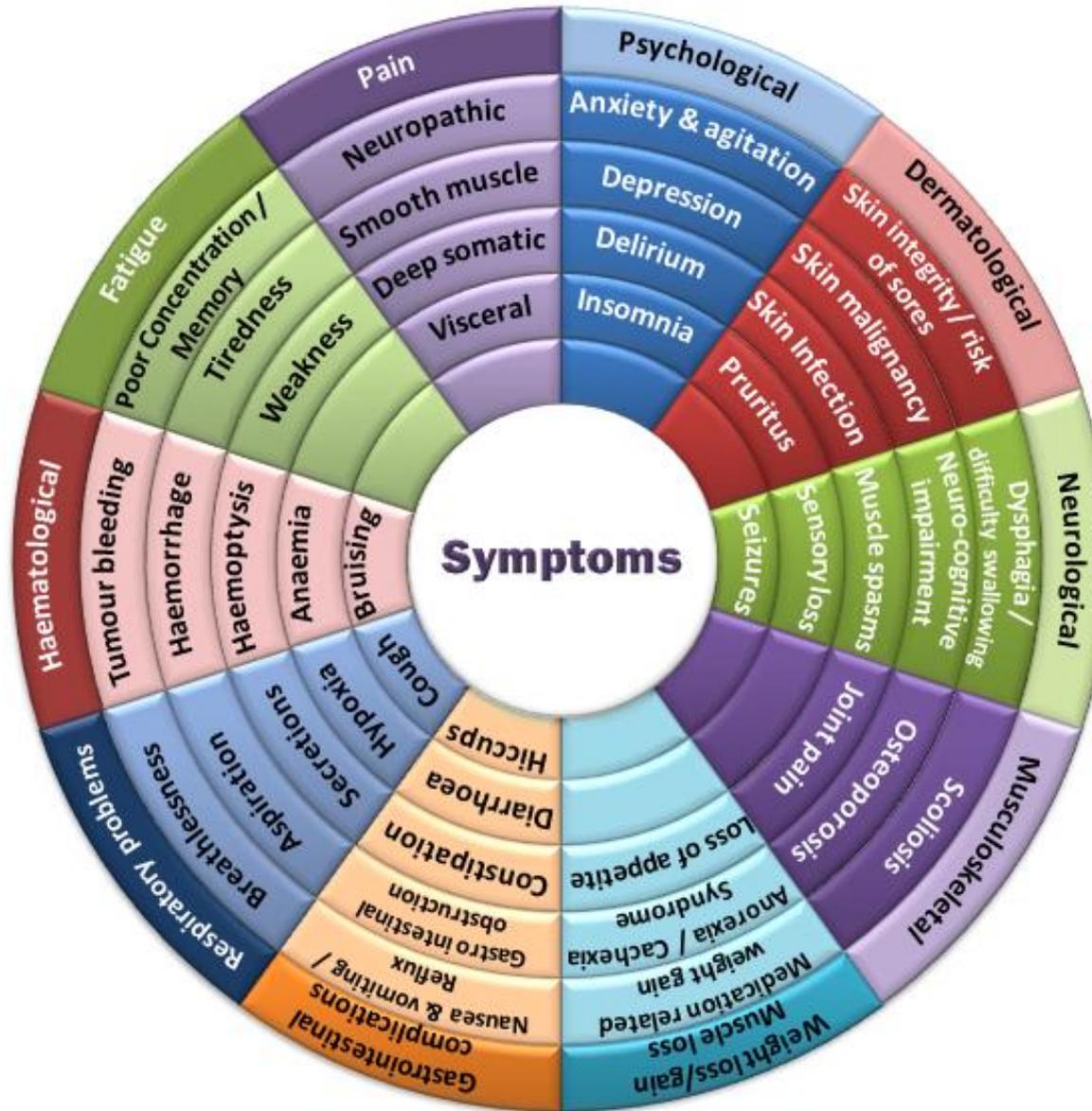
- The wide ranging combination of symptoms, potentially affecting a young person with palliative care needs presents significant challenges for those caring for them. Each young person will experience symptoms differently and the wide range of conditions encountered in palliative care will mean that professionals come in to contact with young people experiencing vastly different types of conditions. *This simple tool is designed to promote thinking about the young person's symptoms;*
- *Helping them to communicate and use direct thinking about their own condition;*
- *What it means to them and how best to help them stay comfortable*

The 'symptom wheel' on page 24 is designed to trigger thinking about the varied symptoms which typically feature within life-limiting illness. Any combination of symptoms, **depending upon condition and stage of illness, may be experienced by a young person now or in the future.**

The role of the key worker or the person undertaking key working is not to assess symptoms or to recommend any type of treatment. Their role is to ascertain if symptom management or pain is an issue for the young person and adequately planned for during transition. If symptom management or pain management is an issue, the key working role is to make sure that the young person is signposted to seek reassessment from their healthcare team. If the person undertaking the key working role is also a member of the young person's healthcare team they may wear two hats (key worker and health care professional) and may address the health needs identified as part of their key working role.

See appendix 1 Thomas', Katie's and Cynog's profiles for examples on how a young person's symptom management needs can be captured in a person centred way.

Figure 5: Symptom Wheel



2. Managing my symptoms and keeping me comfortable

NAME

DOB:

AGE:

DATE COMPLETED:

These are some of the symptoms I experience as part of my condition

This is how my symptoms affect me day to day

These are some of the things I would like you to be aware of which can sometimes make me feel unwell or make my symptoms worse

This is how I usually feel when I am unwell

This is how you can best support me when I feel unwell to help make my symptoms better

Sometimes I can experience (INSERT E.g. Absence seizures). This is how best to support me when this happens (direct to protocols)

For information on how to best support me when I am in pain please see my pain profile

3. My worries and concerns, and how best to support me and my family

Psychological support is central to palliative care for children, young people and adults and their families; reducing the distresses of living with a life limiting or life threatening condition is a primary concern.

This tool is designed to provide a flexible framework for identifying and recording with the young person the ways in which they and their family feel they can best be supported to respond positively to their anxieties.

See appendix 1 Thomas' profile and Katie's profile for examples on how a young person's worries and concerns can be captured in a person centred way.

3. My worries and concerns and how best to support me and my family

NAME

DOB:

AGE:

DATE COMPLETED:

These are some of the things which worry me when I am not feeling well

Sometimes I can become anxious, scared or upset and these are some of the signs you should look out for to tell if I am anxious

There are some things you can help to organise which make me less anxious, scared or upset (e.g. sensory room, music, art work, going outside)

Being anxious, scared or upset can affect me in the following ways...

When I am upset or scared my family can become worried and upset too and this is how they like to be supported when they see that I am upset and worried

4. How best to support me with short breaks and respite

This tool should be used **in conjunction** with the following person-centred planning tool which captures the complex needs of the young person:

- My Perfect Week

The tool is available at: www.helensandersonassociates.co.uk

- Short breaks and respite are an integral part of palliative care for children, young people and their families and for adults receiving palliative care. Short breaks can be a highly valuable source of restful rejuvenation and reduce social isolation. *This tool allows young people, with their families and carers to communicate;*
- *What they value about short breaks.*
- *What types of short break they prefer and feel they benefit from and;*
- *What key aspects of their care needs they feel are important for others to know about when they are being supported to access, plan and prepare for a short break.*
- *This information will be important when thinking about what respite is available to the young person in adult services.*

One of the challenges with transition planning for young people with life-limiting and life-threatening conditions is that there is no equivalent to the short breaks provided by children's hospices. Adult hospices do not commonly provide short breaks on a long term basis, so key workers will need to have a good knowledge of what short break care is possible locally.

See appendix 1: Thomas' profile and Katie's profile for an example of how short breaks/respite needs and preferences can be captured in a person centred way.

4. How best to support me with short breaks and respite

NAME

DOB:

AGE:

DATE COMPLETED:

These are the aspects I enjoy most about having short breaks

These are a list of the things that are really important to take with me when I go on a short break

Who I like/would like to come with me on short breaks or to support me whilst I am on a short break

These are some of the things I need some support with on short breaks and how best I would like to be supported

This is who you should contact in an emergency to let them know if I am unwell

INSERT PHOTOGRAPH OR DRAWING OF FAVOURITE MEMORIES FROM PREVIOUS SHORT BREAKS/OR IDEAL FUTURE SHORT BREAKS

5. What is important for you to know about my mobility, and how to support me with transfer?

Young people with palliative care needs often require support with mobility and transfer during the course of their condition. This is particularly the case for young people with progressive neurological conditions. A young person may require varying degrees of support or assistance to transfer or mobilise and this may include assistance by hoist or use of a specially adapted wheelchair.

Responding to the mobility needs of young people sensitively and competently is critical. Familiarity with the mobility needs of a young person is aided by use of this simple tool. The focus of the tool is to;

- *Support a young person to communicate their mobility needs and specifically;*
- *The tool is designed to provide young people and their carer with an opportunity to record with clarity how best to support them with their mobility needs and what they are able to do.*

For some young people changes in mobility may be gradual whilst for others more rapid, and a young person may have declining mobility as they grow older and enter adult services. The role of a key worker is to make sure that the young person is signposted to the appropriate services so that mobility needs are anticipated and proactively met by the relevant services.

See appendix 1 Thomas' profile and Cynog's profile for examples on how a young person's mobility and transfer needs can be captured in a person centred way

NAME

DOB:

AGE:

DATE COMPLETED:

5. What is important for you to know about my mobility and how to support me with transfer?

This is how I mobilise

What support I require to mobilise

These are some of the difficulties I experience

These are some of the activities I enjoy being able to achieve and that are important in my life (e.g. names of sports, games, social events)

How you can best help me overcome some of the day to day challenges

In order to be able to do these things, I require the following types of support/equipment

6. Nutrition, food, and drink

Young people with palliative care needs often require specialist support with diet and nutrition. This may include a special diet to help them manage their condition or may involve having support or assistance to eat and drink. Some young people with swallowing and breathing problems may need nutritional assistance such as a gastrostomy.

It is important to know how the young person likes to be supported with these specialist needs. A young person may be able to manage many of their own nutritional needs with minimal support or may require more assistance.

The role of the key worker is to link with professionals and services to ensure that as appropriate nutritional needs are captured in transition plans.

See Appendix 1, Thomas' and Cynog's profiles, for examples on how a young person's nutritional and dietary needs can be captured in a person centred way.

NAME

DOB:

AGE:

DATE COMPLETED:

6. My nutritional needs

How you can support me with my meals and drinks

Things that are important for me not to eat or drink (e.g. due to allergy/reaction with tablets etc.)

Some special considerations when supporting me with my dietary needs

Where I like to have my meals/to be supported with my diet needs

If a young person receives dietetic or nutritionist support details of how best to/when to contact them may be placed here

Next Steps: Key Working and Multi-agency Liaison

When an initial composite picture of the young person's palliative care needs is available, the key worker turns their attention to considering, anticipating and addressing identified needs during transition and into adult services. The aim is to ensure that the young person's palliative care needs feed into their transition action plan to help them experience a smooth and positive transition to adult services. Achieving this frequently requires creative thinking as often there is no equivalent adult service.

References

ACT (2007) The Transition Care Pathway, A Framework for the Development of Integrated Multi-Agency Care Pathways for Young People with Life-threatening and Life-limiting Conditions. ACT: Bristol

ACT (2009) A Guide to the Development of Children's Palliative Care Services 3rd edition. 2009. Report No.: ISBN 1 898 447 09 8.

Noyes J, Pritchard A, Rees S, Hastings R, Jones K, Mason H, Richard Hain R, Victoria Lidstone V. (2014) Bridging the Gap: Transition from Children's to Adult Palliative Care. Bangor University, United Kingdom.

Appendix 1: Case Studies

The following three case studies represent fictional composites of young people with palliative care needs. They show how these tools can be completed by/with young people and their families with different conditions. Some young people may not need all of these tools.

These tools could then be used to direct thinking about those particular considerations relating to a young person's condition which need to be addressed in the transition.

For Thomas' case study (Case study 1), the transition checklist and action plan tool is used and informed by the six tools. A one page profile for Thomas can also be found on page 41. This draws together information from the tools to capture what those who currently care for Thomas in children's services, and in future adult services need to know.

CASE STUDY 1: Thomas' profile

Example of completed tools

1. **My pain profile**
2. **Managing my symptoms and keeping me comfortable**
3. **My worries and concerns and how best to support me and my family**
4. **How best to support me with short breaks and respite**
5. **What is important for you to know about my mobility and how to support me with transfer?**
6. **My nutritional needs**

Thomas is 17 years old and lives with his mum and dad and his younger brother James and his sister Lizzie. They have a golden retriever dog called Sandy and Thomas has grown up with Sandy who is an important part of the family. Aged 4 years old Thomas was diagnosed with Duchene Muscular Dystrophy. His family had not heard of this condition before and had been prepared by doctors for the possibility that Thomas may not live beyond his early teenage years. Thomas' muscle strength has weakened significantly in the last three years and since the age of 10 Thomas has needed to use a wheelchair. Thomas is very sociable, a natural leader and enjoys being around others and plays with his local village wheelchair football team. Thomas is close to his grandparents who visit them at least once a week. Thomas is very talented in IT and has gained a place on a graphic design course at his local college. In the future Thomas would like to be a computer game designer.

1. My pain profile

NAME: THOMAS

DOB:

AGE: 17

DATE COMPLETED:

Important things I would like you to know about my pain

When I am in pain it is usually my arms and legs which are affected the most and I get spasms and cramps in my muscles. I also get pain sometimes in my stomach and the medication I take can cause this. When I'm in pain I sometimes go really quiet and don't talk much but I like to be around people as I can get upset. It's important that I am positioned comfortably in my chair when I'm in pain as being uncomfortable can make my pain feel worse.

These are some of the symptoms I often experience alongside my pain

I can get anxious and I sometimes go quiet. When my pain has been really bad I have not wanted to talk to people but I don't like to be left on my own. Occasionally if my pain is really bad then I start to get a headache as well or to feel a bit sick.

How my pain affects me day to day

If I have pain in the mornings it can make me not want to go to college as I can't concentrate. This upsets me because I really enjoy going to college where I'm studying computer graphic design.

These are things you need to be aware of which sometimes trigger my pain ...

My pain is sometimes made worse if I am not sat comfortably in my chair or when my chair needs to be assessed again for me to maybe have a new one or some change to it. Otherwise my pain is usually not as bad unless I need my doctor to look at my medication again.

What you can do to best support me when I am in pain

When I'm in pain I like someone to stay with me and to make sure I'm comfortable. If my pain is really bad I may need to see my nurse or doctor. If my pain's bad at night then I like to have my room door kept open so someone can hear if I need them to come and help me. Luckily I haven't suffered from bad pain for quite a few weeks.

This person knows my condition well and how best to support me:

Relationship: Support Worker
You can contact them using their contact details:

2. Managing my symptoms and keeping me comfortable

NAME: THOMAS

DOB:

AGE: 17

DATE COMPLETED:

These are some of the symptoms I experience as part of my condition

I sometimes get really bad spasms and pain in my muscles especially my arms and legs. This can be really painful and makes me worried sometimes that it will never go away. Because of my medication I get some problems with my stomach. I haven't had bad stomach problems recently but I need to see my doctor when I do.

This is how my symptoms affect me day to day

My symptoms can make me worried sometimes but I am mostly used to them. Because my arms are now weaker than they were a few years ago I find it hard sometimes to write things or to pick up cups or things and I need someone to support me with these things more often now.

These are some of the things I would like you to be aware of which can sometimes make me feel unwell or make my symptoms worse

When I am feeling unwell I like to have some time to rest and don't like to be around lots of people except for when I am worried about things I usually find it helpful to talk with someone who knows me well. I don't like to be left completely on my own and I can't stand people not explaining to me what they are doing if I'm being cared for in hospital.

This is how I usually feel when I am unwell

When I'm not feeling very well sometimes I have stomach pain and feel really uncomfortable. Sometimes I get cramps in my muscles and this can be really painful in my arms or in my legs. I get really worried when this happens and need to be helped to take the medication the doctor has given me to help with this regularly. This can sometimes happen at night and I will need to have someone to come and sit with me if this happens.

This is how you can best support me when I feel unwell to help make my symptoms better

By listening to my concerns and just making sure I am able to get to see the doctor when I need my medication to be looked at or if I need to go to hospital because I am very sick which has happened before you will need to phone for an ambulance and show them my care plan and what medication I am on. I need help to wipe my mouth sometimes because I have problems swallowing I need my carers to help me but I don't always like to ask even though I know them well so I would like you to just ask me sometimes if you think I may need some assistance.

Sometimes I can experience (INSERT E.g. Absence seizures). This is how best to support me when this happens (direct to protocols)

Please read carefully through my pain profile. I like to update this with my carers and key worker so that people know how my pain affects me.

For information on how to best support me when I am in pain please see my pain profile

3. My worries and concerns and how best to support me and my family

NAME: THOMAS

DOB:

AGE: 17

DATE COMPLETED:

These are some of the things which worry me when I am not feeling well

When I'm not feeling very well sometimes because of some of the medication I take I can have an upset stomach. This can make me feel uncomfortable and can be painful and I worry about being able to go to college or someone forgetting to help me take my medication.

Sometimes I can become anxious, scared or upset and these are some of the signs you should look out for to tell if I am anxious

I can feel upset or scared, which sometimes I do when I am unable to do things without help like writing or making a drink. This makes me feel really frustrated because I used to be able to do lots of these things before. I also worry about not having people to help me if I need to go somewhere or want to join my friends when they meet up and some of them who I used to meet up with at the hospice are not very well.

There are some things you can help to organise which make me less anxious, scared or upset (e.g. sensory room, music, art work, going outside)

When I'm anxious or worried about things I like to talk to people and I like spending time watching my favourite television programmes as these help to distract me for a little while. When I am at the hospice and I am upset about something I get to go with one of the nurses there to the hospice gardens where we can have a chat and this helps make me feel calmer because they have very relaxing gardens and really amazing views of the countryside.

Being anxious, scared or upset can affect me in the following ways...

When I'm anxious I can sometimes feel unwell as if I want to be sick. Being anxious also makes it difficult for me to express how I am feeling so I need you to have lots of time to listen to me and allow me to speak. I like to be around people and to have someone reassure me and work out ways for me to carry on being able to do things like meet with my friends and carry on with my wheelchair football.

When I am upset or scared my family can become worried and upset too and this is how they like to be supported when they see that I am upset and worried

My mum gets very upset sometimes. I can tell when she is upset and I know she doesn't always like to talk about it. I think she probably feels more worried when I get sick or need to go to hospital overnight. My mum and dad and my brother and sister get support from the hospice and I think they find this really helpful. I think it's just important for them to have somebody to talk to really because I don't think they want to talk to me sometimes about things that worry them in case they upset me especially because I know my condition is getting worse and I need more care. We all enjoy it when we got to go on a break at the hospice and all got to do our own things which was fun.

4. How best to support me with short breaks and respite

NAME: THOMAS

DOB:

AGE: 17

DATE COMPLETED:

These are the aspects I enjoy most about having short breaks

I really like going on breaks at the hospice because this means I get to meet up with my friends there and we also go for days out to various places where I feel I can relax and have some time to myself. When I go on breaks I like to go bowling and there are always lots of staff to help me. If the weather is nice we also get to go to the seaside.

These are a list of the things that are really important to take with me when I go on a short break

I need to make sure that I take my medication with me but the nurses at the hospice always take care of this. I also need to make sure that I have important telephone numbers with me so that in an emergency my family can be contacted. I like to take my favourite DVD's with me when I go away on a short break and also my mug which I got on my birthday with a photo of our family holiday to Cornwall on it.

Who I like/would like to come with me on short breaks or to support me whilst I am on a short break

When I go on short breaks I always have a named support worker at the hospice. This is usually Ben who is really helpful and you can have a good laugh with. He makes sure I've had my medications and also encourages me to meet young people my age who go to the hospice. We go to the cinema or bowling and once we went to the Zoo. I like to have time away from my parents on short breaks!

These are some of the things I need some support with on short breaks and how best I would like to be supported

I need some help with things like being able to write or draw and sometimes to pick things up. I also need help at meal times with my gastrostomy when I am away on a break and to look after my gastrostomy, but the nurse who comes with me helps me with this. Sometimes I can have pain and if this happens please make sure that I am positioned comfortably in my chair. I have a pain profile which has information about this.

This is who you should contact in an emergency to let them know if I am unwell

My mum and dad's home contact details and address are...

My consultant at the hospital is Dr Jones in the children's department and her secretary's number is...

INSERT PHOTOGRAPH OR DRAWING OF FAVOURITE MEMORIES FROM PREVIOUS SHORT BREAKS/OR IDEAL FUTURE SHORT BREAKS

NAME: THOMAS

DOB:

AGE: 17

DATE COMPLETED:

5. What is important for you to know about my mobility and how to support me with transfer?

This is how I mobilise

I mobilise using my specially adapted electronic wheelchair which I am able to use independently. I need help when I get out of bed using a manual hoist and sling which are kept in my room. I always use the large sling which is colour coded green. Sometimes I need help to turn my wheelchair around and appreciate it when my carer helps me by guiding me but allowing me to control the chair.

What support I require to mobilise

In order to be able to get about I need to be supported to transfer in to my wheelchair using my hoist and sling. I need to be assisted by two people for this. I do not like being assisted in a hurry as it can take me time to get comfortable in the hoist and to be positioned comfortably in my wheelchair. I need plenty of space to manoeuvre my chair and I do not like to be in spaces which are too crowded.

These are some of the difficulties I experience

Sometimes people speak to me from behind when I am in my wheelchair. This can be unsettling as I may not know who they are and I find it difficult to tell what they are saying. I also find it difficult when I go to town and to the cinema with friends because they don't always have wide enough ramps and sometimes the lifts don't work or are too narrow for my chair.

These are some of the activities I enjoy being able to achieve and that are important in my life (e.g. names of sports, games, social events)

I enjoy playing wheelchair football once a week at my local leisure centre. I have lots of good friends at wheelchair football and we recently won a regional competition. Next year I would like to become the team captain.

How you can best help me overcome some of the day to day challenges

You can help me by asking me what aspects of my mobility I need support with, There are some things I am able to do for myself and I can manoeuvre my wheelchair using the electronic controls. Sometimes when I'm tired I need more help to pick things up or to write. This can frustrate me.

In order to be able to do these things I require the following types of support/equipment

When I go out I need someone to come with me to be able to help me get my wheelchair in and out of the minibus. I need a minibus to come and pick me up to take me to hospital appointments and to the hospice which I visit sometimes. I also use a hoist at home when I need support to transfer.

NAME: THOMAS

DOB:

AGE: 17

DATE COMPLETED:

6. My nutritional needs

How you can support me with my meals and drinks

I need assistance at meal times as I use a gastrostomy for nutrition. I find it frustrating having a gastrostomy but I am quite used to it now and as long as the person helping me is someone I know and get on with well then I am happy for them to assist me as I am not able to do this myself.

Things that are important for me not to eat or drink (e.g. due to allergy/reaction with tablets etc.)

I don't have any allergies that I know of. I use a gastrostomy for nutrition. It is important take your time when supporting me with my gastrostomy nutrition and this needs regular re-assessment.

Some special considerations when supporting me with my dietary needs

When I am being supported at meal times I like the person supporting me to be someone who knows me well and who has helped me before or is shown how to by someone who has helped me lots of times before with my gastrostomy. It happened a long time ago, but my gastrostomy tube got blocked once and we had to phone the consultant who helped us. Try not to panic if something like this happens, just make sure you contact my nurses or doctor for advice and explain to me what you are doing. I like to be involved in my own care as I don't like to be ignored. The nurses at the hospice I go to have helped me lots of times and they would always be willing to help. It's important not to rush at meal times and to ask me where I'd like to sit as sometimes I like to be near friends if I am out or on a short break.

Where I like to have my meals/to be supported with my diet needs

Because I have a gastrostomy for my diet I need someone to help me with my diet. I still like to sit with others at meal times though and don't like to be taken away to another area. I sometimes like to go out with my family as well when they have a meal as I enjoy the atmosphere.

If a young person receives dietetic or nutritionist support details of how best to/when to contact them may be placed here

Mr Green Peas
Dietetic Department
High in the Valleys Hospital
South Wales
Telephone:
Fax:
E-mail:

INSERT PHOTOGRAPH

What do others like and admire about me?

Determined, out-going, full of fun, a great team player, friendly, kind and generous.

Thomas' One Page-Profile

How best to support Thomas

What's important to Thomas?

- To be able to **go to college where I am studying computer graphic design**. I get upset if I can't go due to my pain.
- That people explain what they are doing when caring for me, I don't like to be kept in the dark.
- To be around lots of people who I know well.
- To **play wheelchair football**. I play every week at the Leisure Centre and love meeting up with my mates there. We recently won a regional competition, and next year, I really want to be team captain!
- **To be able to go to the hospice as not only is it great fun, and we get to do lots of different things like bowling and going to the seaside** if it's nice weather, it's also a help to my family which I know is really important too.
- To take **my favourite DVD's and my special birthday mug** with me when I go to respite.
- **Spending time with my brothers and sisters** watching a film, listening to music and just having a laugh.

When we go out to the cinema or other exciting place, it's useful to phone ahead to make sure that they have the ramps I need and that the lifts are working. I really hate it when I get all the way to where I want to go, then can't get in because their equipment has broken.

- I have pain in my arms and legs along with spasms and cramps in my muscles. I get stomach pains due to my medication.
- Support me by offering me appropriate pain relief (see my care plan), making sure that I am sitting comfortably in my chair.
- Stay with me as I don't like to be on my own, and during the night, keep my bedroom door open so that I know that you can hear me if I need you.
- If it gets really bad, support me to see my doctor or nurse, or know that you may need to dial 999.
- Make sure that I am positioned properly in my chair as if not, it can make my pain worse.
- If I am unwell give me time to rest in peace and quiet, but check this with me as I don't always like to be on my own.
- My arms have become weaker and I find it difficult to write and pick things up. Support me by asking if I need help, I will tell you what I want you to do.
- Work with me to update my pain profile regularly.
- When we go out, reassure me that you have my medication and a list of important phone numbers with you. I will relax and enjoy myself much more if I know this.
- I have a gastrostomy and like to be supported with this by someone who is confident. At mealtimes, ask me where I would like to sit, and explain to me what you are doing.
- If it gets blocked, keep calm and phone my doctor or nurse for advice.
- I have a specially adapted electronic wheelchair, which I can use independently. Sometimes I need help to turn it around, help me by guiding the chair, but allow me to control it.
- I use a hoist and sling to get in and out of my bed and into my wheelchair. Use the large green sling which is in my room, and remember to talk to me and tell me what you are doing, and don't speak to me from behind me. I don't like to be hurried, it's important that I'm in a comfortable position. I need two people to help me with this.
- I use a minibus to get out. I need support to get my wheelchair in and out.

KEY WORKER PALLIATIVE CARE TRANSITION CHECKLIST AND ACTION PLAN

1. Are the young person's palliative care needs optimally managed now or do they need re-assessment?

Comments:

- Thomas' pain management does not appear to be optimal at the moment and the progressive nature of his condition means that as he grows older and then enters adult services his pain might become worse and his care needs are likely to increase.
- Thomas is currently managed by children's services.
- This is a timely opportunity for Thomas and his family to be introduced to the adult neuromuscular service who will be able to help Thomas and advise on managing his ongoing condition-specific pain issues.

Action:

- To facilitate re assessment of Thomas' pain management and muscle spasms.
- To liaise with appropriate children's and adult teams to facilitate a transition clinic for Thomas and his family.
- To facilitate introduction of the adult neuromuscular team to Thomas and his clinical team in children's services so that they can be familiarised with and jointly assess his ongoing needs through transition and into adult services.

2. Are age appropriate evidence-based tools being used to assess and monitor their palliative care needs (e.g. pain assessment tools, My QuOL_I)?

Comments:

- Age appropriate evidence based tools are not presently being used to assess Thomas' pain.
- Thomas finds it difficult to see patterns in his pain and to judge variation in his symptoms. This means that appropriate support is required to enable Thomas to better articulate his pain and how severe his pain is as well as the way in which it affects him on a daily basis.
- Similarly, Thomas' symptoms can come and go and this has been the case for Thomas in terms of his muscle spasms in the past.

Action:

- To liaise with Thomas' care team to offer Thomas appropriate self-assessment and monitoring tools and teach him how to use them as part of his self-management.

3. Has the young person and their family been signposted to appropriate self-care and self-help guides?

Comments:

- Thomas has not yet been signposted to any self-help guides or programmes for his pain management.
- Thomas and his family may benefit from being introduced to an appropriate supplementary expert pain management programme, which could form part of Thomas' pain management. This has not yet been done.

Action:

- To explore an appropriate expert pain self-management programmes for a young adult with DMD with Thomas.

4. What aspects of the young person's condition do you need to familiarise yourself with to better understand the nature of their palliative care needs and anticipate future support?

Comments:

- I have a lot of condition-specific knowledge to support person centred transition planning with Thomas.

Action:

- To keep updated on Thomas's condition-specific needs as and when appropriate.
- To ensure that information can be shared with adult services such as social workers and occupational therapists so that Thomas' specific and changeable needs are accommodated in adulthood.

5. What are the likely or potential condition-specific palliative care needs as the young person grows older?

Comments:

- Thomas' condition is neurological and progressive.
- Thomas' symptoms will become more severe with time and he is likely to experience further muscle weakness, swallow problems and potential weight gain in forthcoming years.
- Thomas is at risk of serious medical complications such as heart and lung problems or infections. These could occur gradually or more suddenly and unexpectedly.
- As Thomas grows older he is likely to require re-assessment of the suitability of the equipment he needs both at home and in care settings to support his mobility. This may include slings and also his powered wheelchair.
- The progressive nature of Thomas' condition means that there is a strong likelihood these needs will change frequently and that Thomas will want to maintain as much of his independence as possible and as safely as possible into his young adulthood.
- Thomas and his family are supported by a very effective

occupational therapist with whom they have a strong and established rapport and who helped the family access the bespoke mobility equipment Thomas needs to help him mobilise and transfer.

- There is currently no link or transition plan between the children's occupational therapy service and the adult service which has different organisational arrangements.
- The adult occupational therapist has experience of supporting young men with Thomas' condition and how best to support Thomas and his family with the particular challenges around Thomas' diagnosis.

Action:

- To anticipate and plan ahead to proactively rather than reactively meet Thomas' needs over time. See also 1 above.
- To facilitate a plan so that specialist occupational therapist support is continued beyond children's services and that if Thomas and his family do have to change occupational therapist, a thorough and phased 'handover' is facilitated from one occupational therapist to another with involvement of adult physiotherapists from the neuromuscular service for adults.

6. Are there appropriate adult services to help the young person manage their potentially fluctuating or escalating palliative care needs once they leave children's services?

Comments:

- Yes – partially. There is an established and well experienced neuromuscular service available to Thomas within his locality which has expertise with Duchene Muscular Dystrophy and the associated physical health issues.
- Thomas will likely need to access adult hospital wards (respiratory, cardiology and potentially intensive care) should he become suddenly or unexpectedly unwell with a chest infection or because of heart muscle weakness for example.
- A big concern for Thomas is that if he should fall ill suddenly as an adult he will not be able to go straight to the children's ward as he has done previously. This is for safety reasons and reflects the different policy and care pathways in acute adult services. There is no equivalent adult hospice service.
- Thomas' GP currently has little involvement as he is managed by a community paediatrician.

Action:

- To work with Thomas and his family to prepare for admission to adult services. The differences and the reasons behind admission pathways in children's and adult services need to be explained

honestly and thoroughly. This will help reassure Thomas that his well-being is at the centre of decision making and will manage his expectations proactively.

- To liaise with service providers to facilitate a process of joint clinics (e.g. adult respiratory/breathing doctors and nurses).
- To review Thomas' care package in the near future to take account of his longer term care and support at home, at college and in the community, to ensure that in adult services there is the flexibility for additional support for Thomas as his condition progresses and his ambitions for the future remain.
- To work towards integrating the GP into the process of managing care looking forward.
- See point 7 re adult hospice service.

7. Are adult services aware of any potential palliative care management issues with the young person?

Comments:

- No - not in a person-centred way. Thomas' pain and symptom management needs are complex and in relation to Thomas' own perceptions are outlined in his one page palliative care need profiles.
- Adult neuromuscular services will be generally aware of the complex palliative care management issues around Duchene Muscular Dystrophy but have not yet Met Thomas (see also 1 above).
- The adult hospices however, from whom Thomas may require or request support in his early adulthood are unlikely to be experienced in managing neurological conditions at end of life in young adults.

Action:

- To support Thomas to communicate his needs and wishes with appropriate adult services so that they proactively become aware of Thomas' palliative care needs.
- To facilitate continued involvement of Thomas, his family and carers in his care assessment and in providing a safe and supported network for Thomas to discuss his future needs and hopes which are really important.
- To support adult services to continue the family centred ethos practiced within children's services to maintain a personalised and young adult centred delivery of care without losing sight of the details which are important to Thomas as he grows older and lives with the inevitable challenges of his condition.

8. Do the adult professionals and services require up skilling and planned orientation during transition and beyond to prepare for taking over management of the young person?

Comments:

- Yes, it is crucial that all adult services that Thomas comes into contact with and his GP are oriented both to the condition specific and continuity of family centred needs and ongoing communication.
- Adult hospice staff in particular may require specialist training or support from children's professionals.

Action:

- To make contact with the appropriate services so that up skilling can be proactively initiated in preparation for taking over Thomas' person-centred management.

9. Has/have the young person's palliative care need(s) been considered jointly by appropriate paediatric and adult services?

Comments: No not yet.

Action:

- To engage adult services in this non end of life oriented approach to palliative care provision to ensure appropriate services are offered to Thomas.

10. What is the best way to facilitate smooth transition to the most appropriate adult services for this particular young person?

Comments:

- There is an existing process for transferring young people with DMD from children's to adult neuromuscular services – but young people who have been through transition report that the 'handover' has not worked well and young people have felt abandoned and lost in adult services.
- Continuity of a family centred approach can help mitigate this negative experience by making sure that Thomas is thoroughly involved in decision making about his own care and that, as required by Thomas, he is able to make important decisions with the support of and guidance of his family, who throughout Thomas' life have made decisions with and for him about his care.
- Thomas' care package/funding will need revising in response to many changes in practical care needs and the level of support he requires at college (e.g. designated support/one-to-one support etc.).
- It is vital that Thomas' access to counselling and bereavement support is maintained through the children's hospice for as long as possible and then from an equivalently specialist adult

bereavement service. This is important because some of Thomas' friends with the same condition as him may die in forthcoming years and this will be a difficult time for Thomas emotionally, raising lots of anxieties for him about his own future.

Action:

- To facilitate the process of familiarisation with Thomas' adult care providers of Thomas' care needs and the ways in which his condition affects him so that they can best support Thomas through the progression of his condition.
- To initiate regular contact with Thomas' family and his primary carers to ensure that Thomas' anxieties are sensitively managed in a timely way. To facilitate liaison between children's and adult services through Thomas' transition care plans and influence best practice for working together at multi-disciplinary meetings.
- To facilitate integration of health transition plans with education reviews or through separate transition service reviews where these teams are in place.
- To support the respective health services to facilitate phased transition clinics between child health and adult specialist practitioners to create a less disjointed transition to adult services for Thomas.
- To facilitate a thorough handover of and family engaged re-assessment of Thomas' support needs with his College to allow Thomas to fulfil his potential as he progresses each year through his course.

11. If no appropriate adult service exists or no adult service can flexibly accommodate the young person's needs how is this information going to be proactively fed back to commissioners, the young person and parents?

Comments:

- Thomas and his family can continue to access the counselling services and respite on offer through his local children's hospice until age 25 years. Thereafter children's provision ends.
- The local adult hospice has limited experience of offering this type of service to younger adults.
- The GP will have access to information about local condition-specific support groups for adults, for families and also more specialist allied health and social care professional support whose services may benefit Thomas. This could also include day care/rehabilitation facilities, locally, which cater for young adults needs and where facilities of interest to Thomas are available and where funding can be sourced to provide access to these for Thomas and his family.

Action:

- To engage the GP to identify appropriate referral channels for psychological support that may be funded and available to Thomas and his family in adult services.

12. Are there any other alternatives worth considering? E.g. apply for continuing care funding, direct payments, referral outside of region or to private provider?**Comments:**

- Direct payments for social care could be explored.
- In the future continuing care funding may be an option to consider.

Action:

- To ascertain Thomas' perspectives on direct payments and how he would like to manage his services.
- To monitor Thomas' changing needs and match with the threshold for applying for continuing care funding.

13. What plans are in place within children's/adult services to support the young person and family in the event of sudden/unpredictable or unforeseen exacerbation or end of life palliative care management needs?**Comments:**

- Thomas knows that his condition will get worse as he gets older and that he may develop very serious complications affecting his heart and lungs.
- Thomas is anxious about this, and, tends to hide this well most of the time, so it's crucial to be available to Thomas so that he can share his worries and have someone there to listen to him and reassure him as to what processes are in place to ensure rapid assessment in hospital admission for adults.
- Thomas has an advanced care plan and an end of life care plan. This needs to be used in conjunction with Thomas' standard and palliative care plan around his likes and dislikes and hopes and ambitions for the future so that Thomas can continue to do the things he enjoys regardless of his condition.
- No plans are yet in place to facilitate initial liaison with appropriate adult services. Thomas' children's consultant and the children's hospice have been really helpful in providing lots of reassurance and understandable information.

Action:

- To arrange equivalent support needs in adult services.
- To arrange for Thomas to meet the adult hospital doctors who can explain to Thomas why the process of going to hospital if he is unwell in an emergency will be different once he is 18 years old and that he will not be able to go straight to the children's ward instead

of A&E if he is unexpectedly unwell.

14. How often does the young person's palliative and complex care plan need reassessing and revising to meet changing needs and condition-specific life course?

Comments: Thomas' needs are likely to progressively change over time.

Action:

- To proactively review every 6 months and after any significant change.

15. Is planning for 'what if' scenarios sufficient? (E.g. what plans are in place if the young person becomes acutely unwell during transition, or recovers suddenly from an end of life situation?)

Comments:

- No planning for 'what if events' such as acute admission to hospital during transition have yet been undertaken.

Action:

- In the immediate future to ascertain Thomas' wishes and put clear plans in place for an admission pathway to hospital. See also 6 – preparing for transfer to adult services.

Date completed: 14th March 2014

Prepared by: John Smith – Key worker

Revisit date: September 2014 – or sooner if a significant event occurs.

CASE STUDY 2: Katie's profile

Examples of completed tools

2. **Managing my symptoms and keeping me comfortable**
3. **My worries and concerns and how best to support me and my family**
4. **How best to support me with short breaks and respite**

Katie, age 14 years, was diagnosed six months ago with Hodgkin Lymphoma, a type of cancer that affects the system in the body responsible for fighting infections. This is an extremely rare type of cancer for children to get. Katie has found her diagnosis very distressing and hard to understand and her condition has made her anxious about her future. Katie does not have any brothers or sisters. Katie requires chemotherapy. Katie is very close to her grandmother who visits often and spends evenings with Katie if her parents are at work. Katie has lots of friends at school and also at the hospice where she has been on two occasions for a short visit and has met some young people her own age. Katie loves pop music and listens to her favourite CDs almost every day.

2. Managing my symptoms and keeping me comfortable

NAME: KATIE

DOB:

AGE: 14

DATE COMPLETED:

These are some of the symptoms I experience as part of my condition

Because of the treatments I can become really tired sometimes and don't feel like I have the energy to do anything. This can make me a bit irritable sometimes. Because of the treatment I've had I am not supposed to go out much in case I get an infection but when I go to the hospice they make sure I am kept safe and can still spend time with other people my own age.

This is how my symptoms affect me day to day

I feel upset sometimes because I am not allowed to spend time with lots of my friends in case I pick up an infection. I get to spend time with people my own age at the hospice when I visit but I haven't been able to go out on trips recently because of my treatment. I got to go on the last trip to the seaside though.

These are some of the things I would like you to be aware of which can sometimes make me feel unwell or make my symptoms worse

When I was first ill I had swelling under my arms. This wasn't painful but it made me feel uncomfortable. If this happens I need to see my consultant straight away. I am not supposed to be in crowds while I have my treatment but I'm ok to spend time with a few friends inside the hospice when I am there on a break.

This is how I usually feel when I am unwell

On a bad day I feel very weak. Recently I've lost some weight and this has made me feel upset because I know people notice this. I can also get very tired and usually become quite quiet or not want to see my friends. I can stop feeling hungry as well and I know this worries my mum and dad.

This is how you can best support me when I feel unwell to help make my symptoms better

When I feel unwell I can feel very weak so I need someone to help me to do things like put my music on. I like to be with my mum if I'm not well or with my grandma if she is visiting us. I don't like to talk much when I'm not feeling well but this doesn't mean I want to be left on my own. I like to have my bed changed quite often as I can get sweating at night because of my condition and this makes me feel uncomfortable.

Sometimes I can experience (INSERT E.g. Absence seizures). This is how best to support me when this happens (direct to protocols)

Sometimes I might get a fever or sweating which I had when I was first diagnosed. I need to be in hospital if I get really unwell so the doctors and nurses can look after me.

For information on how to best support me when I am in pain please see my pain profile

3. My worries and concerns and how best to support me and my family

NAME: KATIE

DOB:

AGE: 14

DATE COMPLETED:

These are some of the things which worry me when I am not feeling well

When I don't feel too well I don't really feel like talking to people and sometimes I can be agitated and come across as short tempered and tired. If I'm not feeling well it's important to me not to have too many people with me but I like to have my mum or dad with me because they know when I'm not feeling well and how to help me.

Sometimes I can become anxious, scared or upset and these are some of the signs you should look out for to tell if I am anxious

When I'm scared or upset it's usually because I have to go to hospital to see the doctor. I'm quite used to going now but I still get nervous and don't like hospitals. I find them too big and busy. I will probably become a bit panicked and maybe get upset if I know that I've got to go to hospital so I need plenty of support when I go and someone to explain to me everything that's happening.

There are some things you can help to organise which make me less anxious, scared or upset (e.g. sensory room, music, art work, going outside)

I tend to be calmer and reassured when I am with my mum and dad. I like spending time with my friends at School and I like doing art work which also helps to relax me if I'm feeling worried about anything. I like to draw at home too and mum has a display in the house of some of the painting I've done.

Being anxious, scared or upset can affect me in the following ways...

I can sometimes become quite upset and agitated. This usually happens if I know I am going to the hospital. This can make me not want to go out and I sometimes only want to talk to my mum or dad or maybe the nurse who knows me well and comes to visit us at home sometimes, her name is Stacey. It's important to listen to me when I'm upset and to find out why I am not feeling happy.

When I am upset or scared my family can become worried and upset too and this is how they like to be supported when they see that I am upset and worried

My mum and dad can be upset when they see that I am not happy or scared about something. It's important that they have somebody to talk to as well and they get to speak to Stacey when she visits too. Mum and dad like to go out sometimes with each other and when they go I have a carer who comes and looks after me or my grandma does sometimes. Me and my grandma get on really well and she always makes me jam sandwiches which I really like.

4. How best to support me with short breaks and respite

NAME: KATIE

DOB:

AGE: 14

DATE COMPLETED:

These are the aspects I enjoy most about having short breaks

I really enjoy going on short breaks with the hospice. We get to go on day trips to different places and do lots of activities in the hospice. There are some other people my age there sometimes and I like to spend some time with them as we get to watch films or play music in the young person's room. My favourite type of music is any pop music but I don't like loud rock music.

These are a list of the things that are really important to take with me when I go on a short break

I need to take my medication with me but my mum and the nurses who look after me at the hospice sort this out for me. I also need to take my diary as I like to write down the things I've done during the day. I also like to take my favourite music CDs with me.

Who I like/would like to come with me on short breaks or to support me whilst I am on a short break

When I next go on a short break I'd like to have my main support worker with me as she is really helpful and makes sure I haven't forgotten to take anything. Sometimes I can get a little bit upset being away from mum and dad at first so having my support worker with me makes me feel much better and we get to write a list of the activities I'd like to do during my short break. I can't go on a short break at the moment though until my body is a bit better and I am safer from infections which I might pick up more easily.

These are some of the things I need some support with on short breaks and how best I would like to be supported

When I'm on a short break I like to be able to go on the different days out they take us on from the hospice. Sometimes we go to somewhere like the seaside and when we stay at the hospice I like to meet other people my age and watch films and talk. If I start to feel unwell though I can get tired so I need someone to be able to make sure I get plenty of rest otherwise I am unable to do some of the other activities I like do like the music group.

This is who you should contact in an emergency to let them know if I am unwell

My mum's name is... and my dad's name is... Our home address is... and their telephone number is...

My consultant at hospital is Dr.....and his number is...

INSERT PHOTOGRAPH OR DRAWING OF FAVOURITE MEMORIES FROM PREVIOUS SHORT BREAKS/OR IDEAL FUTURE SHORT BREAKS

CASE STUDY 3: CYNOG'S Profile

Examples of completed tools

1. **My pain profile**
2. **Managing my symptoms and keeping me comfortable**
5. **What is important for you to know about my mobility and how to support me with transfer?**
6. **My nutritional needs**

Cynog is 22 years old and lives in the countryside with his mum and dad. Cynog has an older brother who has left home and lives about an hour away from Cynog. Cynog was diagnosed with Global Developmental Delay when he was a small child and doctors said this was due to a problem with Cynog's brain and spinal cord. Cynog requires full support to maintain a steady state of health and social well-being. He enjoys interaction with others and responds positively to sensitive humour. Cynog recognised familiar voices and enjoys the company of his family. Cynog has access to the sensory room at his local hospice and this noticeably relaxes him. Cynog's mum and dad and carers feel it is important for Cynog to be able to continue to access this type of facility for years to come.

1. My pain profile

NAME: CYNOG

DOB:

AGE: 22

DATE COMPLETED:

Important things I would like you to know about my pain

Cynog can have pain sometimes and finds it difficult to communicate that he is in pain. It is important whilst looking after Cynog to note any expression of pain as sometimes Cynog will begin to appear agitated or restless when he is in pain. It's really important to monitor Cynog's agitation and to speak to his GP about this if it becomes frequent as Cynog's medication may need to be reviewed.

These are some of the symptoms I often experience alongside my pain

Cynog can appear agitated and restless when he's in pain. Cynog may also seem withdrawn or disinterested in what is going on around him and this is unusual for Cynog who loves to be around people and to interact with others.

How my pain affects me day to day

Cynog's pain can mean that he is less interested in taking part in different activities such as art or going outside which Cynog always seems to enjoy and benefit from, becoming more alert and interactional. This is unusual for Cynog so when he does experience pain and physical discomfort it has a significant impact on his well-being and on what he is able to be supported to do.

These are things you need to be aware of which sometimes trigger my pain ...

Cynog seems to show signs of being in pain when he is around people he doesn't know very well or hasn't met before, so it's important to make sure that Cynog has lots of support from familiar people and has plenty of time to get used to a new carer with other people with them until he has become used to their voice and presence.

What you can do to best support me when I am in pain

When Cynog's in pain it's important to make sure that Cynog has received his medication to help him manage his pain. Cynog is best supported by having people around him with whom he is familiar and can reassure him. If Cynog appears to be in lots of pain or very agitated or restless especially for a long time, so more than a couple of hours, then it's best to contact the doctor to come and see Cynog or to call his consultant or specialist nurse for some advice.

This person knows my condition well and how best to support me:

Relationship: Mum

You can contact them using their contact details: Home contact details

2. Managing my symptoms and keeping me comfortable

NAME: CYNOG

DOB:

AGE: 22

DATE COMPLETED:

These are some of the symptoms I experience as part of my condition

Cynog can sometimes have seizures. These usually happen in the morning and last less than a minute. Sometimes Cynog's seizures are fairly small seizures and other times he will have a seizure where his entire muscles contract, we call this a tonic clonic seizure. Cynog sometimes needs help to suction saliva from the sides of his mouth if too much is produced. It's important to help Cynog with this using his suction machine so he doesn't choke.

This is how my symptoms affect me day to day

When Cynog has a seizure this can make him very tired for a long time afterwards. This means that going out somewhere for the day or doing any activities such as art or music with Cynog would have to be rearranged so that he can enjoy these activities when he has fully recovered and is able to interact as he would normally do without being further exhausted.

These are some of the things I would like you to be aware of which can sometimes make me feel unwell or make my symptoms worse

After Cynog has had a seizure he doesn't like to be around noise or lots of people as he becomes very tired. Cynog tends to become very withdrawn and quiet when he feels unwell and may not appear as interactional. It's important not to overload Cynog with activities or take Cynog to busy places when this is the case.

This is how I usually feel when I am unwell

After a seizure Cynog is extremely tired for a long time, sometimes a few hours and will not be able to take part in activities such as music, art or going outside where he may be over-stimulated. Cynog usually starts to stare in a particular direction and not respond to verbal interaction for a few minutes before he has a seizure so this is a warning sign to look out for. When Cynog is generally not feeling very well he tends to go very quiet and does not make as much eye contact as usual.

This is how you can best support me when I feel unwell to help make my symptoms better

Cynog responds really well to hydrotherapy at the hospice when he is feeling well. This tends to help Cynog feel more relaxed and he always appears to enjoy spending time in the swimming pool where he is responsive to interaction with carers and his physiotherapist. It's important to know what to do if Cynog has a seizure during hydrotherapy and Cynog should always be supported by two trained professionals.

Sometimes I can experience (INSERT E.g. Absence seizures). This is how best to support me when this happens (direct to protocols)

There is a guide on what to do to support Cynog when he has a seizure in his care plan and anyone caring for Cynog should have good knowledge of seizure first aid.

For information on how to best support me when I am in pain please see my pain profile

NAME: CYNOG

DOB:

AGE: 22

DATE COMPLETED:

5. What is important for you to know about my mobility and how to support me with transfer?

This is how I mobilise

Cynog uses a wheelchair to mobilise and will need someone to operate his wheelchair for him. Cynog can become distressed if his wheelchair is moved or turned too suddenly so it's really important to be careful of this and to also make sure that Cynog is positioned comfortably in his chair. The chair is specially adapted for Cynog. Cynog needs to be assisted using a hoist for transfers and two people are needed for this. It's important to keep talking to and reassuring Cynog as you do this.

What support I require to mobilise

Cynog needs to be supported with transfers such as to his bed using a hoist. In the hospice there's an overhead tracking system which can be used to assist Cynog with hoist transfers. Two people are needed to support Cynog with his transfers. It's really important to ongoing reassurance to Cynog and to explain what you are doing and take your time. Cynog enjoys the company of others and verbal reassurance and interaction can enormously reduce his distress when being assisted to mobilise.

These are some of the difficulties I experience

Cynog can find it difficult to communicate if he is uncomfortable in his wheelchair, so it's really important to monitor Cynog and to pay close attention to his facial expressions in case he appears to be uncomfortable or needs his chair re-assessed by an occupational therapist.

These are some of the activities I enjoy being able to achieve and that are important in my life (e.g. names of sports, games, social events)

Cynog enjoys being outside in the fresh air and smiles when he is assisted in to the garden in his wheelchair. Cynog always appears to be relaxed by the sounds of the outdoors and by being around other people talking to him. Cynog doesn't like loud noise and it is important to Cynog that he is not taken to locations which will be known to be too noisy.

How you can best help me overcome some of the day to day challenges

To best support Cynog to live his life to the fullest it's important to observe closely whether Cynog appears comfortable and make sure that Cynog is supported to be able to go outside into the garden and out for walks when appropriate so that variety and quality in his life is maintained.

In order to be able to do these things, I require the following types of support/equipment

It's important that Cynog is supported in a safe environment where there is a hoist and appropriately sized and fitted sling for him. You should always check all the equipment before assisting Cynog. Cynog has a specially adapted wheelchair. Cynog needs to be supported to remain comfortable so it's essential for Cynog that his position in the wheelchair and indications of comfort are monitored.

NAME: CYNOG

DOB:

AGE: 22

DATE COMPLETED:

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Appendix 2

Transition Key Worker/Key Working in Palliative Care:

Adaptation of Role Specification/key Worker Function

Adaptation of current Transition Key Worker role specification/ key worker function

Integrating the generic role with meeting palliative care needs and supporting personalised outcomes

Integrated Care and Support

1

Single point of contact for the child, young person and their families and responsible for co-ordinating services. **Providing a link and signpost to specialist services to support a young person and their family with aspects of pain and symptom management therefore working to help ensure that adverse symptoms are minimally disruptive to a young person's life and to do so in a motivated and approachable manner.**

Key knowledge, skills and attributes:

- **Knowledge of work of children's and adult palliative care services, interdisciplinary working and diversity of symptoms frequently encountered in young people with palliative care needs** and able to signpost to those health professionals involved in helping a young person manage these symptoms.

2

Co-ordinate and gather information that is timely, up to date, accurate, accessible and relevant and to apply this within the context of advanced care planning with young people and families. **The key worker must ensure that this is broached at an appropriate time, sensitively and with a developmentally appropriate approach to communication with a young person about their future hopes and care preferences, inclusive of the family unit in decision making and drawing upon main caregiver/parental experience in managing a young person's condition.**

Key knowledge, skills and attributes:

- Ability to establish strong and trusting relationship with a young person and their family and to work inclusively with the family unit, respectful of and **attentive to the family's needs and concerns.**
- To be familiar with and competent in, or willing to engage in training in communication methods such as Makaton or sign language as appropriate.
- To be a **natural communicator**, an **active listener** and able to provide emotional support often during highly unsettling periods for a young person and their family.
- Familiar with and attuned to own personal well-being needs and best use of available mentorship.
- A **highly organised individual with some experience in or training in administrative skills or document management** or a strong willingness to undertake training in this.

3

Ensure that plans support statutory planning in health, social care and education and approach the well-being needs of a young person through an integrated approach valuing their social, educational and health needs as inter related. To ensure that the palliative care needs of a young person are not lost in more generic service planning and to involve, where appropriate and desired by a young person other more specialised services which may be able to cater specifically for a young person's needs.

Key knowledge, skills and attributes:

- To have, or be **capable of acquiring and developing own knowledge of local services across health, education, social and leisure sectors** and to be able to apply this knowledge and liaison with other services relevant to and appropriate to each young person's needs.
- To be conversant with the essence of and ethos of person-centred care planning.
- To be **aware of the specific issues and challenges and sensitivities particular to the context of palliative care** for young people.

Personalised Care and Support

4

Ensure that the needs and wishes of a person are central to care planning and reviewing and that care planning is embracing of a person-centred approach. **A Transition Key Worker in palliative care will support a young person and their family to prepare for and contribute to person-centred annual statutory reviews** ensuring integration of continuity of multi-agency care between educational, health (primary and secondary care), social care and third sector professionals in meeting the psychological and social well-being needs of a young person: central to the provision of effective palliative care. A Transition Key Worker will therefore have excellent skills in communication with a diverse range of professionals and negotiating complex care systems.

Key knowledge, skills and attributes:

- **Has received training in or has practical experience of using person-centred approaches to care planning with young people and their families or a willingness to engage with person-centred care planning and use of specialist palliative care person-centred planning tools.**
- **Enthusiastic about and with a commitment to thinking first and foremost about what is important to and for a young person in terms of their well-being and quality of life. What they would like to be able to achieve in life and where they prefer to be cared for.**

5

Help and support children and young people and families to identify their needs and aspirations for now and in the future, helping a young person and the family through fulfilment of an **on-going emotionally supportive role through the combination of active and palliative treatment often characteristic of children's palliative care and helping a young person and their family to access specialist support organisations where required and maintaining dynamic awareness of the young person's changing care needs.**

Key knowledge, skills and attributes:

- Good observational skills to support a young person and family to access appropriate specialist support.
- **Ability to research the availability of and remit of local support services in the third sector** (which may be condition specific) and national support groups which may be able to provide some support to a young person and family; emotional, financial, advisory and/or practical.
- To be comfortable with **emotionally supporting a young person and family** during times of unpredictability and to have an understanding of the changing care needs of a young person, especially with a degenerative condition.

Continuity of Care and Support

6

Co-ordinate and monitor action plans and ensure those tasked to undertake an action are committed to achieving this in a timely fashion so as not to interrupt the continuity of a young person's holistic care. Part of this role would involve effective sign posting so that involvement of all key stakeholders in a young person's care planning is secured.

Key knowledge, skills and attributes:

- Essential that a Transition Key Worker has **experience in or training across both health and social care sectors** and an awareness of the strategic workings of both sectors in order to be able to liaise between both to ensure that a young person's needs are not lost or that services provisioned for the young person are not lost.
- To have a **motivating influence** on other services who provide care and support for the young person and family; ability to and preferably **experience of engaging multi-agency professionals to communicate on a regular basis** about how best to complement one another's work and support a young person to reach their full potential.

Supporting Independence

7

Support children and young people to maintain & develop friends and relationships. To help young people access age and developmentally appropriate services such as day care, respite and leisure facilities as required and to provide a safe and supportive environment in which a young person can socialise and learn new skills.

Key knowledge, skills and attributes:

- To be **actively engaged in communicating with local young people's services**, ensuring their appropriateness for young people with specific needs such as mobility, transport, medicinal or nutritional needs and to work within a person-centred model, using person-centred planning tools and resources to capture these specific needs and to communicate them with other service providers.
- **To be an advocate for a young person** when this is needed to ensure that they are not discriminated against with respect to access to local services and facilities which form an essential part of their social life and well-being.
- Able to **communicate adaptably** and **develop a natural rapport** with a young person and their family to gain as much information as possible about what is important to and for a young person to best support organising their care around what they would like to be able to do and achieve.

8

Support children and young people and their families where there may be a difference of opinion and work with them to resolve this with emotional sensitivity. To consider foremost what is important to the young person who has a life-limiting or threatening condition and to establish their concerns and anticipations for the future. To plan sensitively with a young person and their family, taking due account of their belief and culture. The future of a young person is central and integrating advanced care planning and end of life considerations (ie parallel planning) without neglecting commitment to planning ahead should be a key priority of a transition key worker. A key worker should co-ordinate and advocate for a young person's continuing access to rehabilitative palliative treatments where beneficial to the young person.

Key knowledge, skills and attributes:

- **Close attention to detail** around the young person's own hopes and ambitions for the future, and ability to integrate support with and sign posting to advice with managing complex symptoms, worries and concerns.
- **Ability and willingness to establish close working relationships with the wider multi-disciplinary team around a young person** including doctors, nurses, occupational therapists, physiotherapists, psychologists and social workers to foster a network of specialist support covering key aspects of a young person's care needs.
- **To have an awareness of the roles and remits of different health and social care professionals.**

9

Be proactive and creative in developing new opportunities for children and young people. Provide support and encouragement to a young person who when in stable health wishes to plan ahead for their future despite living with an unpredictable course of illness. To use person centred planning tools flexibly and creatively with a young person and their family to communicate individualised needs to other health and social care professionals who may not be as familiar with the young person.

Key knowledge, skills and attributes:

- **To be creative and approachable, to be willing to work with a young person and their family and as part of a team** with other professionals to capture the detail of a young person's unique personality and individual needs
- To be aware of and interested in how a young person's condition and physical, psychological and social care needs are important to them and affect them as an individual.
- To be able to **help a young person communicate their needs with carers and other professionals** in adult services.

10

Provide emotional and practical support and be proactive and in regular contact to ensure that a 'steady state' is maintained, or ensure that the child or young person and their families remain in a 'steady state' and are prepared for the changes ahead. Be open to and prepared to listen to and support a family regarding their concerns about end of life care and care needs and engaged with providing bereavement support throughout the young person's journey through transition.

Key knowledge, skills and attributes:

- **Knowledgeable of bereavement support organisations regionally and nationally** which families can be sign posted to as appropriate and willing to listen to a young person and their family's concerns about the future and anticipation of end of life care.
- **To support a young person with sensitivity to communicate their care preferences and needs around particular care domains using person centered planning tools.**
- To be committed to using these tools to share important information with adult service providers with whom the young person may at first be unfamiliar and who will need to be engaged with planning ahead for the young person's future, **embrasive of and always prepared to provide and co-ordinate support for, but not unduly preoccupied with end of life care needs.**


Hope House
Children's Hospices



PRIFYSGOL
BANGOR
UNIVERSITY


together
for
short
lives

Pantio'r Bwlch
Bridging the Gap
 **tŷ hafan**

THE UNIVERSITY OF
WARWICK

 **ccnuk**
care co-ordination network uk
the key working charity



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

