



*Helen & Douglas House*

## **Transition and Beyond**

# TOOLKIT






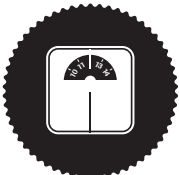






*For professionals working with young people who have palliative care needs*

*The authors and editors have, as far as it is possible, taken care to ensure that the information given in this toolkit is accurate and up-to-date at the time it was created. Helen & Douglas House is not responsible for the content of external websites. Users are advised to confirm that the information complies with current legislation and standards of practice. Since palliative care and associated commissioning arrangements are part of an evolving process, the current toolkit will be modified when required.*

*Clare Periton-Edwards, Director of Clinical Services at Helen & Douglas House commissioned the development of this pack to contribute towards improving practice. This work was co-ordinated by Helen Carter, Independent Healthcare Advisor with help from her colleagues Sarah Goodwin and Jo Carter. Contributions were received from Clare Periton-Edwards, Liz Leigh, Lynda Price, Will Mitchell, Emily Harrop, Shahina Haque, Lucy Wells, Karen Brombley, Laura Klepping, Rawle McCarthy, Briget Valusiakova and Chris Bloor. The designer was Chris Woodrow ([design@chris-woodrow.co.uk](mailto:design@chris-woodrow.co.uk)). Thanks are extended to patients at Douglas House who shared aspects of their life journey for this toolkit.*

*All scenarios used in this toolkit are based on real situations. Where possible the young adults have chosen their own pseudonym to maintain confidentiality.*

*July 2014*

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# Foreword



# Foreword

Douglas House opened in 2004 as a response to the lack of palliative and supportive care services for young people whose mortality had exceeded the expectation of those responsible for admitting them, at some point in childhood, to the care of Helen House Children's Hospice.

Having shared the journey to early-adulthood with around twenty-five young people Helen House found it difficult to abandon them. As a consequence a successful capital appeal raised funds to build and equip Douglas House, a unique Hospice specifically for young adults (to the age of 35 years).

Some of the young adult graduates of Helen House were consulted on the proposed building's design relative to their needs. The architects took cognisance of their comments and as a consequence a bar, a sound-proofed music room and art room were provided – and extra width was added to Douglas House's main corridor to facilitate wheelchair races.

Whilst the young adults were consulted on the building little thought was given to the emotional and psychological support they required to help them come to terms with leaving childhood. Initially the focus was predominantly on 'fun' in a super-duper building and the underlying perception, albeit not verbalised, was that a special space was being created for 'bigger children'.

It was only after the initial razzmatazz had faded that the members of the Douglas House Care Team realised the full extent of the task of caring for and supporting cognitively-aware young adults as they strive for autonomy from parents, deal with issues of gender identity, and come to terms with their own mortality. To this can be added feelings about career, lifestyle choice, intimate relationships and the internalisation of morality – the developmental tasks of young adulthood (Newman & Newman, 1995).

The evolution of adult consciousness (Gould, 1978) in young adults who have profound and multiple impairments (including severe intellectual impairments) added another very significant dimension to the work of the Care Team at Douglas House.

This toolkit (*Transition and Beyond*) draws heavily on the experiences of Douglas House's journey in the years 2004 to 2014. Had it been available twenty years ago I, and the health, social care and educational professionals with whom I then interacted on behalf of my son, would have been spared much frustration and anger, as we negotiated the measures and resources necessary to support my son's transition from adolescence to young adulthood.

I commend this toolkit to you and hope that it helps you and your young adult clients to put measures in place that truly enhance their lives.

A handwritten signature in black ink that reads "Tom Hill". The signature is written in a cursive, slightly slanted style. Below the signature is a horizontal line that starts under the first letter and extends to the right, ending under the last letter.

**Tom Hill**

Chief Executive, Helen & Douglas House







# Introduction

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# Introduction

*'Elaine is now 19 years old and going through her transition was horrible; it was the worst experience of our lives. Our daughter was entitled to home care. It was difficult trying to get professionals to talk to Elaine as an adult in her own right and not as my child.'*

*Mother, July 2013*



***Transition in healthcare has been a process to get young people to adapt to us and the services we provide rather than us adapting to the needs of young people.***

Gleeson and Tuner (2011)

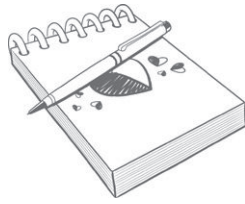
We all have periods of transition during our life and a well-recognised life transition occurs during adolescence.

It is notable that healthcare services create a further transition for young people where service provision is traditionally focused on children or adults. Whilst the focus on young people is becoming more common, there has been limited medical literature about the process of transition from child to adult services. Unfortunately there continues to be poor co-ordination across statutory and voluntary sectors.

The purpose of this toolkit is to equip clinical staff with an understanding of the process of transition for young people with life-limiting illnesses. It covers physical, social and emotional development, including aspects of legal and social norms that can impact upon a young person's decision making.

Helen & Douglas House, where Helen House accepts people aged 0-18 years old and Douglas House accepts people aged 18-35 years old, staff come across a number of complexities where children mature into adults at different times. Douglas House patients are often placed on children's wards when they need to go into hospital but are expected to function in an adult environment when in respite care.

This toolkit is not intended to be a comprehensive or in-depth analysis of transition. However it does provide an introduction to this key aspect of development for young people. We hope it will stimulate you to explore the subject of transition further.



## Activity 1

**In order to make full use of this toolkit, undertake this reflective activity.**

Consider yourself at 16 years old and recall your hopes, ambitions and aspirations. Write them down. Now try to reflect upon those thoughts having been given a diagnosis of cystic fibrosis when you were younger:

- ♥ How do you feel?
- ♥ What do you want to happen?
- ♥ What does your future look like?

If you have kept a diary or journal from your teenage years you may find it useful to go back to it and re-visit that period.

Adolescence is an essential process of physical, cognitive and emotional change in the move to independent adulthood. Physical independence from parents and peer group identification are essential to adolescent development. Achieving the goals of adolescent development can be extremely complex and difficult for young people with life-limiting and life threatening illness. Some young people may have been progressing through normal adolescent development before the onset of an acute life threatening illness. For young adults with progressive disorders adolescent development may coincide with deteriorating physical and/or mental health.

There is a need for effective collaboration between adult and children's palliative care services to support young people adjusting to this important life change. Craft and Killen (2007) recorded that current arrangements were rarely ideal and could result in the sudden transfer of young people to adult services.

Alternatively they can remain in children's services for too long. The on-going limited availability of adult services also impacts on transition for younger people.

This toolkit looks at the challenges and opportunities for young people with life-limiting conditions, making the transition from childhood to adulthood at the same time as they will be experiencing a move into adult services. Clinical staff are not always aware of the difficulties young people have when developing new relationships with carers and professionals. The impact can be more pronounced when changes come at the same time as saying goodbye to an established team of care staff. The toolkit will provide clinical staff with the opportunity to consider these challenges and enhance your understanding of transition. There will be a number of activities for you to work through and guidance is given for further reading to enhance your learning.

# Definitions

Teenagers and Young Adults with Cancer (TYAC) and the Teenage Cancer Trust identify that teenage and young adults fall into distinct groups with transition needs. The age range can vary from ages 15-18 year olds at initial presentation up to ages 24-25 year olds at a later presentation requiring transition into adult services.

The concepts of palliative care and transition are complex. At its simplest transition is the process of changing from one state or condition to another. Ginsberg et al (2006) identified the following barriers to transition in the table below.



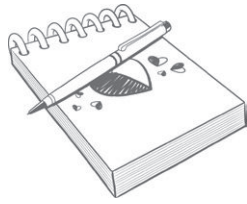
***The patient may exhibit dependent behaviour, immaturity, severe illness, disability, psychopathology, lack of trust in care givers and poor adherence to treatment.***

***The family may have an excessive need for control, emotional dependency, psychopathology, over protectiveness, lack of trust in care givers and heightened perception of disease severity.***

Ginsberg et al (2006)

***Transition is 'The purposeful, planned process that addresses the medical, psychosocial and educational/ vocational needs of young people and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems.'***

*Rosen, D.S. (2003) cited in Doug et al 2009 and recognised as a definition for healthcare by the Department of Health (2006)*



## Activity 2

**What does transition mean to you?**

- ♥ Seek out other definitions.
- ♥ List key features that are important to a successful move through to young adulthood.

### ✓ good practice point

**Transitional care is complex; however the following elements are fundamental:**

1. Consideration must be given to the holistic nature of transitional care and address clinical, psychosocial, vocational and educational issues.
2. It needs to be flexible and developmentally appropriate to meet the changing needs of young people.
3. Care must be taken to meet the needs of the parent/carer.
4. A preparation phase in children's care; a transfer phase from children's care to adult services and an engagement phase in adult services (this gives time to think and plan).
5. Potential interventions to support the process should be considered with a focus on staffing, service delivery, the young person and their parents/carers.

# Further reading

The following documents contain useful information relating to transition. They include information about supporting young people into adulthood; young people making decisions for their own health; best practice guidance and principles for health services to become 'young person' friendly.

**Department of Health (2004)** *National Service Framework for Children. Young People and Maternity Services*. London: Department of Health

**Department of Health (2006)** *Transition: Getting it Right for Young People*. London: Department of Health

**Department of Health (2007)** *A Transition Guide for All Services: Key Information for Professionals About the Transition Process for Disabled People*. London: Department of Health

**Department of Health (2007)** *You're Welcome Quality Criteria*. London: Department of Health

**Newcastle University Transition website**  
Current research into transition and has links to other websites of interest  
<http://research.ncl.ac.uk/transition/index.html>

**Together for Short Lives website for professionals and families**  
[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

## Helpful websites for young people

RESOURCE	WEBSITE ADDRESS
<b>Child and Maternal Health</b>	<a href="http://www.chimat.org.uk/transitions/youngpeople">www.chimat.org.uk/transitions/youngpeople</a>
<b>Newcastle University Transition website</b> Current research into transition focused on the inclusion of young people working with the research team	<a href="http://research.ncl.ac.uk/transition/index.html">http://research.ncl.ac.uk/transition/index.html</a>
<b>Great Ormond Street Hospital</b>	<a href="http://www.gosh.nhs.uk/teenagers/leaving-hospital/preparing-for-adult-health-services">www.gosh.nhs.uk/teenagers/leaving-hospital/preparing-for-adult-health-services</a>
<b>Teenage Cancer Trust</b>	<a href="http://www.tct.org.uk">www.tct.org.uk</a>
<b>Teenagers and Young Adults with Cancer (TYAC)</b>	<a href="http://www.tyac.org.uk">www.tyac.org.uk</a>
<b>CLIC Sargent</b> (Cancer and Leukaemia in Childhood)	<a href="http://www.clicsargent.org.uk">www.clicsargent.org.uk</a>







# Professional Considerations

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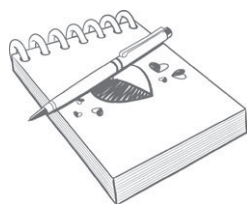
### **Secondary/tertiary care**

#### **Together for Short Lives pathway**

# Support for yourself

Working with children and young people who have life-limiting conditions or who may be dying can be challenging and emotionally draining.

It is essential that staff use the support network provided within their organisation that includes line management support and clinical supervision. The Helen & Douglas House *Clinical Supervision Toolkit* (2011) was devised for professionals working with children and young people who have palliative care needs. This toolkit is available for any organisation to use to support staff. It is available on the Helen & Douglas House website.



## Activity 3

**Identify your professional support mechanisms:**

- ♥ When did you last have coaching or clinical supervision?
- ♥ Book yourself regular clinical supervision sessions.

## Care reviews and transition planning

Professionals should maintain unambiguous communication which is supported by a plan of care to ensure continuity of care for the young person. This is underpinned by the *Communicating with Other Professionals* policy at Helen & Douglas House which sets out the key values of the organisation. The policy is relevant to all clinical staff working within the organisation and can be used, with permission,

by other organisations providing similar services to Helen & Douglas House.

The philosophy underpinning all policies and procedures is to ensure that all care and treatment provided to young adults is well coordinated and that good quality communication with all agencies involved is effective.

**Good communication between professionals is facilitated by:**

- involvement of the young adult and their family (sometimes separately).
- regular multi-disciplinary meetings with all relevant practitioners.
- up-to-date multidisciplinary record keeping.

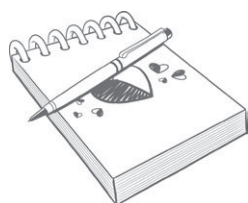
*Continued overleaf*

It is important that transition is seen as a proactive process that involves early planning and preparation that facilitates a successful outcome (Bolton-Maggs, 2006). Life events including changes of staff that the young person is used to, family structure and dynamics can all affect the details of care and treatment.

Transition planning runs in parallel with a period of life when the young person may increasingly wish to express autonomy over the decisions they make about their care. In the early phases, autonomy may be mediated through the adults with parental responsibility. The consent of the parents and/or the young person to share information must be recorded and wherever

possible a copy of the consent given to the young person. This dynamic changes as the young person reaches adulthood and can be responsible for making their own decisions. This aspect often needs careful and skilled communication with parents.

It is good practice to undertake regular reviews, ensuring the young person's views contribute to the multidisciplinary review. It has been recommended that a written individualised transition care plan should be in place by the time the young person is 14 years of age (Viner, 2008) which provides the opportunity to discuss the transition plan and the way forward.



## Activity 4

**Due to the changing needs of the young people who use services such as Helen & Douglas House, action is taken prior to the care review.**

- ♥ Discuss with a colleague and record what needs to happen before a care review.
- ♥ What information do you think would help inform other team members?

## ✓ good practice point

1. Talk with the young person and/or family about any particular information they will be bringing to the review.
2. Advise relevant clinical or key workers (e.g. Lead Consultant) that there is going to be a review and request an update on the young person's condition and health, including the young adult's prognosis and resuscitation status.
3. The transition plan will need to be amended to reflect the particular circumstances.
4. Inform members of the relevant care team.
5. Invite professionals such as the social worker, school teacher and/or contact for each young person with the young person's, or their family's, consent.
6. Ask for and offer a written or verbal report if they are unable to attend.



Where professionals are invited to meetings it is important to seek consent from the child, young person, or parents beforehand. The exception are safeguarding meetings which require all relevant professionals to attend.

## Primary care

Prior to the period of transition it is important to encourage and ensure young people have a constructive relationship with their General Practitioner and other community services. Parents may require support to enable the young person to take the lead in negotiating this relationship.

The GP is often the key point of contact in transition from children's to adult services. Specific conversations at the 'start' of transition, with the GP and all other providers, is good practice to ensure that there is clear continuity of care.

## Secondary/tertiary care

Recent advances in specialist care and treatment have seen children and young people with life-limiting illnesses living to more mature ages than previously experienced. Research has shown a steady increase in the number of children living with a life-limiting condition, particularly in the 16-19 year old age group. This suggests that the growing need for expertise associated with these conditions is being driven by longer survival times, rather than a rise in the incidence of disease.

Fraser et al (2011) noted that the national prevalence of life-limiting conditions in children (aged 0-19 years) in England had increased over 10 years from 25 to 32 per 10,000 population with the final year reaching double previous prevalence estimates.

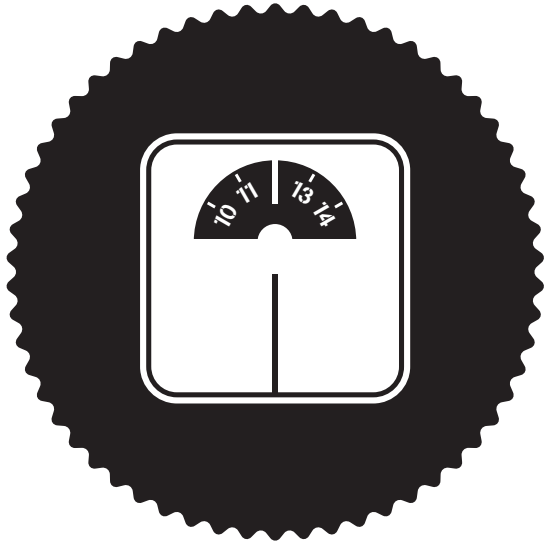
For example Duchenne Muscular Dystrophy (DMD) is considered a progressive disease with an unfavourable prognosis and a limited life expectancy, calculated at the beginning of the adult age (20 years) (Passamano, L. et al, 2012). It has been suggested that DMD should be considered an adulthood disease as well, and as a consequence more public health interventions are needed to support these patients and their families as they pass from childhood into adult age (Passamano, L. et al, 2012).

Although research points to the changing trends in life expectancy it should be noted that specialist services for young people moving into adult services may not be provided in the same way as those in children's services. Wherever possible an adult team with expertise closely related to the condition should be sought. However it is acknowledged that there is often not one Lead Consultant who can co-ordinate treatment and care.

## Together for Short Lives transition care pathway

The Together for Short Lives transition care pathway provides a useful diagrammatic representation of all the considerations that professionals must explore when working with young people. It provides person centred tools, to help young people plan and lead the lives that they want.

[www.togetherforshortlives.org.uk/professionals/care\\_provision/care\\_pathways/transition\\_care\\_pathway](http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/transition_care_pathway)



# Decision-Making

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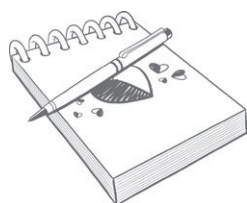


# Who makes the decisions?

This section has been provided to assist you in this challenging area of decision making.

Developing into an adult involves taking an increasing level of responsibility for oneself, including making decisions about a whole range of activities including care. Douglas House has experience of taking patients with a wide range of conditions and while some young people will

require decisions to be made on their behalf, others will have the capacity to make their own choices. The guidance and activities that are in this section will enable you to explore the legal and ethical considerations in the decision making process.



## Activity 5

**It is time to consider the role of parents in the transition from child to young adult, as this is also a period of change for them.**

It is a good idea to go to the document *Making Decisions: A Guide for Family, Friends and Other Unpaid Carers* using the link below.

[www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf](http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf)

- ♥ Who makes the decision for the young person you are working with?
- ♥ Why is this?
- ♥ What implications does the Mental Capacity Act have for young people and their parents?
- ♥ How could a parent be involved in assessing capacity?
- ♥ What is your role in assessing mental capacity?

## Key points to remember about the Mental Capacity Act (2005)

1. It is in place to support and enable people over 16 years of age to make decisions about their own welfare, financial situations and treatment and care.
2. It starts from the principle that anyone over the age of 16 years old is considered to have capacity to make their own decisions, at the time they need to be made, unless it can be demonstrated that they lack capacity.
3. All practical steps must be taken to ensure that the individual has all the necessary information, help and assistance to make a decision. Only after this has been achieved can there be consideration of the individual's capacity to make a decision.



4. It states that an individual has the right to make a decision that others may consider unwise. Although others may consider the decision unwise, the individual should not automatically be labelled as lacking capacity to make that judgement.
5. If care or treatment is initiated under the Act for or on behalf of the individual, it must be in the individual's best interests.
6. Any actions taken for or on behalf of someone who lacks capacity should be an option that is less restrictive of their basic rights and freedoms – as long as it is in their best interests.

Source: [www.direct.gov.uk/prod\\_consum\\_dg/groups/dg\\_digitalassets/@dg/@en/@disabled/documents/digitalasset/dg\\_186484.pdf](http://www.direct.gov.uk/prod_consum_dg/groups/dg_digitalassets/@dg/@en/@disabled/documents/digitalasset/dg_186484.pdf)  
[Accessed: 4th December 2013]

**The assessment of capacity must address the following four aspects:**

→ Can the individual understand the information relevant to the decision to be made, including the consequences of making, or not making, the decision?	→ Can the individual use or weigh up the information as part of their decision making process?
→ Can the individual retain the information?	→ Can the individual communicate their decision?

If the individual has any form of communication difficulty this must be addressed and supportive measures taken to ensure that they can communicate fully.

All related records must demonstrate that the above process has been followed in all regards.

## Acting in a young person's 'best interest'

When a decision is made in someone's 'best interest' many people may need to be consulted. This will include carers, appropriate relatives and health care professionals. However, on reaching the age of 18 no one else can actually consent to treatment for another person – this includes a parent, spouse or next of kin, unless they have been appointed with a Lasting Power of Attorney.

### What this means for the parent/s or their child

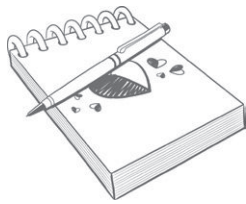
Every effort has to be made to communicate options regarding a decision that needs to be made to a person who needs to make it. The Mental Capacity Act provides a non-exhaustive checklist of factors that decision-makers must work through in deciding what is in a person's best interests.

If a person lacks capacity, relatives caring for the person will be helpful in informing the decision-making process. If the young person lacks capacity and is over 18 the parents may

want to explore applying to become a Court Appointed Deputy. Whilst this does not give them the same rights as previously, it records in law what they must be consulted about. In addition, the Act enables people to plan ahead for a time when they may lack capacity and to put their wishes and feelings into a written statement.

### What this means for professionals

The Mental Capacity Act provides a statutory framework both to protect people who may lack capacity and to empower them to make some decisions for themselves. This could apply, for example, to people with dementia, intellectual impairment or mental health problems who may lack capacity to make certain decisions. This could apply to many of the patients of Helen & Douglas House and similar caring organisations. It makes clear who can take decisions in which situations and how they should go about this.



## Activity 6

**Consider one or more of your clients who may have difficulties making their own decisions.**

- ♥ Write a list of the factors you need to think about when working out whether you are making a decision in their best interest.

*The Mental Capacity Act offers a non-exhaustive list of what you need to think about when working out what is in a person's best interest.*

### Where to find further information:

[www.justice.gov.uk](http://www.justice.gov.uk)

[www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/index.htm](http://www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/index.htm)



# Transition

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# Moving from child focused care to young adult based care

*'Disabled people need a step-by-step guide of what you have to do. You have to know the right people. I had four care managers and they asked me the same stuff over and over again...Going from children's services to adult services was the biggest pain in my arse.'*

*Jack Dawson, July 2013*

***'Our experience was that at aged 19 years old they [previous services and support] dropped.'***

*Initially the community offered care. All the way through this experience there has been one barrier after another. A decision tool was used. The report was good and understandable. It was seen by the panel and good progress was made. A Nurse Assessor from the commissioning team came to do the care plan, which was one sheet of A4 paper. At this time people knew there was more to it. It was positive that she was reviewed as a child and we were asked what would help to keep the family afloat and Elaine in her own home. There was a second care plan which was two sheets of A4 paper which included respite care at Douglas House.*

*The commissioner said "no" there was to be no nursing care, no respite care. Arguments went to and fro. Both of my daughters have 100% "loss of control". I have done quite a lot of the 'medical interventions' (that a Registered Nurse would do) over the years – which is now coming back to bite me! We have been offered residential care. I would like Elaine to be cared*



*for independently at home with appropriate medical care in order for her to be respected as an individual, a young adult, have all needs met, not just her care needs. I feel that my children deserve the best care I can get for them.*

*Communication with Commissioner has been poor; they seem to have had trouble recruiting the right people. There have been stumbling blocks with every turn. We are fighting to get twenty-four-hour care. We are fighting over a college placement. Health is refusing to fund transport as it is not in their remit and social care won't touch it. I have been asked to use my eldest daughter's mobility allowance to fund Elaine. There has been little compassion shown by the Commissioner; Going into Adult Services the notion of "facing challenges" has become "fighting battles".'*

Source: Interview with Mother of two girls with life-limiting diseases, July 2013

## Together for Short Lives transition care pathway

The Together for Short Lives transition care pathway provides a useful diagrammatic representation of all the considerations that professionals must explore when working with young people. It provides person centred tools to help young people plan and lead the lives that they want. The key messages from local experts are to start preparing children and their families early and to set realistic expectations.

[www.togetherforshortlives.org.uk/professionals/care\\_provision/care\\_pathways/transition\\_care\\_pathway](http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/transition_care_pathway)

Nationally a range of services exist to support children, young people and their family. These can mainly be categorised as Statutory Services, Children's Hospices and disease-specific charities. Some children's hospices, such as Helen & Douglas House, will have their own units for young adults. In other situations, health and social care professionals signpost the family to the nearest available unit or to the 'best fit' service available locally.

Many disease-specific charities are well-versed in the complex issues posed by transition. They are often well-placed to help families through the process, drawing on the experiences of other families with related conditions. These can be found in the local Contact a Family Directory. There is also helpful information in the Helen & Douglas House *Palliative Care Toolkit* (2011) available on the Helen & Douglas House website.



***It is a different world and can be a challenge as few services match. In Children's Community Nursing, generalists stay with the children throughout their condition. This is not replicated in adult services, where District Nursing can be intervention-focused. Families tell me they struggle as they have been used to a joined-up system with key professionals and they lose the generalists other than the GP. We are expanding our outreach team at Helen & Douglas House so we can interface better with the rest of the system and add the specialist bit around Advance Care Planning and symptom management.***

Nurse Consultant, September 2013



# Personal health budgets in England

The NHS introduced personal health budgets *'to help people with long term conditions and disabilities manage their care that suits them.'* (Department of Health, 2013). From April 2014 everyone eligible for NHS continuing healthcare funding in England has a right to ask for a personal health budget. All young people/young adults should be informed that they can review and update their care plan when needed – this means their personal health budget should not be means tested (Department of Health, 2013).

*'A personal health budget is an amount of money to support your identified healthcare and well-being needs; planned and agreed between you, or your representative, and your local NHS team.'* (Department of Health, 2013).

## Personal health budgets can be a:

1. notional budget (no money changes hands).
2. budget held by a third party (organisation or trust).
3. direct payment.

This has yet to be tested; however users can assume they are not left to take care of everything (Department of Health, 2013).

## How to get a care review

A long-term condition diagnosis usually means that young people have more contact with the NHS than their peers. They may need to see their GP or hospital specialist for regular check-ups and monitoring or take long term medication.

Consultations with health and social care professionals to talk about the care and support they are receiving are important. The care plan review ensures the needs of the individual are being met and that the goals they set are being worked towards.

**In the review the following are considered for a young person:**

→ Do they continue to be satisfied with the services that have been put together to help support them and, if not, how these can be improved?

→ Are they coping at home with the services provided?

→ Have other things in their lives changed – for example, if their health has improved or deteriorated?

→ Have they achieved the goals set previously in their care plan?

*Continued overleaf*

During the review, the GP or specialist can make sure a young person's condition is being managed in the best way possible. The review is also a time for the individual to talk about how they are coping and any problems they have. A care plan review should be arranged at least once a year. If either party (health professional or patient) feels that the care plan is not

working or other things have changed, a care plan review may be requested. If this is not happening the family may bring this to the attention of their healthcare or social care providers. Alternatively the overall co-ordinator should contact the relevant multi-professional team members as a reminder.

*See also: NHS Choices (2012) Get a care plan review [Online] Available from: [www.nhs.uk/Planners/Yourhealth/Pages/Carereview.aspx](http://www.nhs.uk/Planners/Yourhealth/Pages/Carereview.aspx) [Accessed: 18th December 2013]*

## Resources

RESOURCE	WEBSITE ADDRESS
<b>Website providing information about the Department of Health's personal health budgets policy being rolled out nationally in the NHS</b> It is set up for NHS and social care professionals	<a href="http://www.personalhealthbudgets.england.nhs.uk">www.personalhealthbudgets.england.nhs.uk</a>
<b>To register for newsletters</b>	<a href="http://www.personalhealthbudgets.england.nhs.uk/useraccount">www.personalhealthbudgets.england.nhs.uk/useraccount</a>
<b>Personal health budget newsletter</b>	<a href="http://www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/2013/PBUnewsletterMar2013.pdf">www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/2013/PBUnewsletterMar2013.pdf</a>
<b>Understanding personal health budgets</b>	<a href="http://www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/Toolkit/MakingPHB Happen/Getting messageacross/Understanding_personal_health_budgets.pdf">www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/Toolkit/MakingPHB Happen/Getting messageacross/Understanding_personal_health_budgets.pdf</a>
<b>Easy read version</b>	<a href="http://www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/Toolkit/MakingPHB Happen/Gettingmessageacross/Easy_Read_Personal_health_budgets_2013.pdf">www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/Toolkit/MakingPHB Happen/Gettingmessageacross/Easy_Read_Personal_health_budgets_2013.pdf</a>

# Principles for effective transition from children to adult services

It is widely recognised that services aimed at children and adults vary considerably from one county to another. Helen & Douglas House has established a series of five principles that facilitate an effective transition for young people and their families.



## 1. Early preparation

As transition to adult services can be a challenging time, it is rarely too early to start preparing for the event. In Helen House staff start considering if 14 year olds will progress to Douglas House when 18 years old or whether their condition is stable enough for them to no longer require the support of a hospice. A transfer within the service can be reasonably straightforward compared to referring to services when an individual is not going to continue onto Douglas House.

## 2. Young person or carer involvement (this stage can be undertaken together or separately)

As a progression towards adult services, a child with capacity should be involved in the assessment for, and the provision of, services into adulthood. For those without capacity, carers or family members can act as advocates in the young person's best interest, but once they reach the age of 18 years are no longer able to legally do so, according to the Mental Capacity Act (2005). Despite this it is vital to involve family members in the discussions and planning of services.

## 3. Broad professional involvement

The professionals involved will vary depending on family preference, diagnosis/condition and locality of the young person. It is essential to engage professional colleagues from social services, education and health. Colleagues from health services for children and adults are integral to the success of the transition phase. The family should also be central to any meetings held, ensuring their voices are heard in establishing effective services into the future. A young person's GP is often one of the only consistent professionals across the period of transition.

## 4. Timely discussions

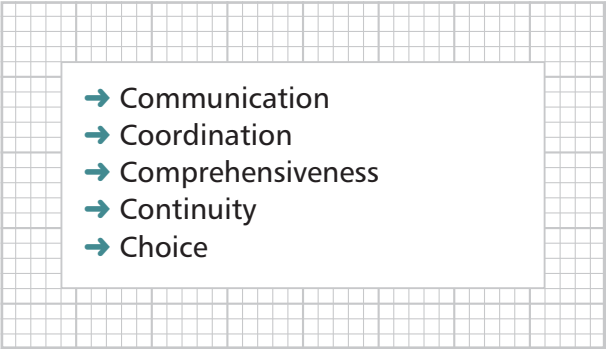
The timing of discussions is vital with regard to the family and young person. It is important to avoid specific times of stress for the family, such as school and national examinations or surgery.

## 5. Honesty with no promises

In any situation it is always easier to add something rather than to withdraw something which might have been suggested. It is important to say that the health or social care professionals can advocate but do not always have the power to make the decisions.

# The 5 'C's of good transition practice

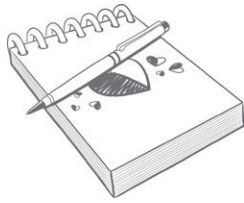
Heslop et al (2002), identify the 5 'C's as elements of good transition practice;

- 
- Communication
  - Coordination
  - Comprehensiveness
  - Continuity
  - Choice

Communication should be open, respectful and honest. It should involve coordinated, effective inter-agency work. The comprehensive nature of the transition process addresses equality issues (such as race and disability) with the expectation that young people have access to the same opportunities as their peers. The identification of a key worker supports the maintenance of continuity of care. Finally the young person and their family require appropriate options so they can make suitable choices.

## ✓ good practice point

It is good practice to identify a 'co-ordinator' or 'key worker' for the transition process. Also, it is easier to reduce the numbers of professionals involved over time than to introduce new ones part way into the process.



## Activity 7

Some areas employ transition co-ordinators, whose role it is to oversee the transition of the young people's care from children's to adult services.

- ♥ Do you know if such a service or role exists in your area or why one would be helpful?
- ♥ If so ensure that you make a note of their contact details and of their role.

## Further reading

RESOURCE	WEB ADDRESS
<b>Department of Education and Skills &amp; Department of Health (2006)</b> <i>Transition: Getting it Right for Young People.</i> Improving the transition of young people with long term conditions from children's to adult health services	<a href="http://www.bspar.org.uk/DocStore/FileLibrary/PDFs/Transition-20getting%20it%20right%20for%20young%20people%20-%2023rd%20March%202006.pdf">www.bspar.org.uk/DocStore/FileLibrary/PDFs/Transition-20getting%20it%20right%20for%20young%20people%20-%2023rd%20March%202006.pdf</a> <i>[Accessed: 2nd March 2014]</i>
<b>Royal College of Nursing (2013) <i>Lost in Transition</i></b> Moving young people between child and adult health services	<a href="http://www.rcn.org.uk/__data/assets/pdf_file/0010/157879/003227_WEB.pdf">www.rcn.org.uk/__data/assets/pdf_file/0010/157879/003227_WEB.pdf</a> <i>[Accessed: 2nd March 2014]</i>





# Life Skills

## **41 Going to college and university**

### **ACTIVITY 8**

## **42 Housing**

## **43 Independent living**

### **Making a complaint about care agencies**

## **44 Joining a gym**

## **45 Bank accounts**

### **Benefit advice**



# Going to college and university

*'I wanted to be a chef...cooking any kind of food, copying the teacher to learn and then eating it... and then I did it at college.'*

*MD, now age 22*

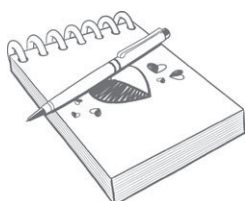
For many children and young people with life-limiting conditions attending school and college brings its own particular difficulties.

It is often not the illness that limits educational achievement but the absence from school due to acute periods of ill health, having to attend medical appointments or having been admitted to hospital. Crucially, school and colleges provide an opportunity to socialise with friends and maintain social interaction.

Young people with severe illness want opportunities to receive advice about educational and vocational options,

as would be expected by their peers. They reported that others tend to make important decisions for them. This has made them feel undervalued, disempowered or angry. Young people with life-limiting conditions report that they are rarely asked "What do you want to do when you grow up?". This implies there is no expectation they will go onto further education or into work.

Consider the following activity:



## Activity 8

**Consider now a young person you know and what they wish to achieve.**

- ♥ Are their goals appropriate in the context of their age, developmental stage, and illness? Are there other alternatives?
- ♥ Consider yourself as an 18 year old who has a life-limiting condition. What challenges may you face making the step to independence by choosing to attend university?
- ♥ Have a go at researching for college or a university of your choice in the area that you choose.

There are colleges and universities as well as specialist colleges for disabled students. These places can prepare residential and day students for the many challenges of adult life by concentrating on the whole person.

## Resources

RESOURCE	WEBSITE ADDRESS
Claverham Community College	<a href="http://www.claverham.e-sussex.sch.uk">www.claverham.e-sussex.sch.uk</a>
Treloar College	<a href="http://www.treloar.org.uk">www.treloar.org.uk</a>

# Housing

Once a young person reaches 18 years old, there are several housing options that might be considered. Many young people continue to choose to live at home, but perhaps have a more significant care package that enables independence from their parents. Others may decide, with their parents, to further adapt the

house to create a more independent area for living. However, some individuals prefer to live independently with support, known as 'supported living'. Alternatively, there is the option available to live away from home in a residential college or university. The film below is recommended viewing.

## Inside I'm Dancing

(Also released as *Rory O'Shea Was Here*)

*'When the kinetic Rory moves into his room in the Carrigmore Residential Home for the Disabled, his effect on the home is immediate. Most telling is his friendship with Michael, a young man with cerebral palsy and nearly unintelligible speech. Somehow, Rory understands Michael, and encourages him to experience life outside the confines of home.'*

Source: [www.imdb.com/title/tt0417791/](http://www.imdb.com/title/tt0417791/) [Accessed: 2nd March 2014]

**Film preview:** <http://www.youtube.com/watch?v=m2X4M3WT0W4>

# Independent living

Parliament's Joint Committee on Human Rights (JCHR) seeks evidence about independent living for disabled people. This right is guaranteed by Article 19 of the UN Convention on the Rights of Persons with Disabilities. The committee particularly welcomes evidence from disabled people and their families about how Government policy and legislation and the activities of public authorities, can implement this right in practice.

In order to aid the transition to a more independent and full life, organisations such as Care Management Services, are set up specifically to provide expert advice, knowledge and help to enable young people to try new things, make their own choices and be independent.

Care Management Services (2014) recognise that even today, *'access can still be difficult, equipment slow and expensive to obtain*

*and specialist care support almost impossible to find, even if it could be afforded'.*

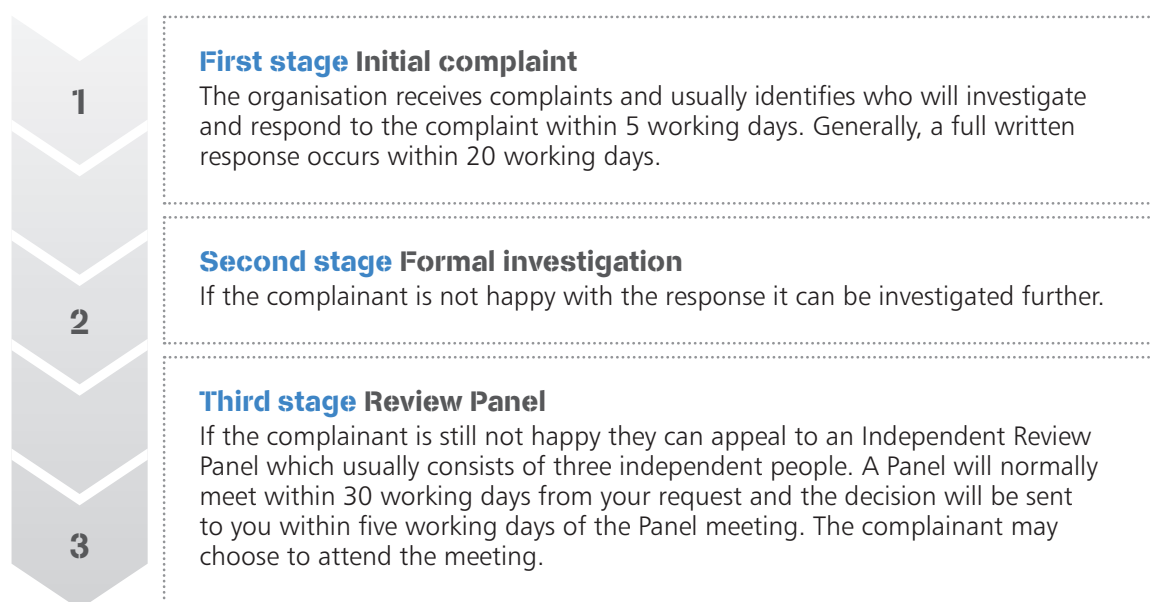
**According to Care Management Services, problems with care agencies can include:**

→ inflexibility.	→ poor emergency cover.
→ high staff turnover.	→ poor staff training.
→ lack of client control.	→ unreliability.

The Care Management Services website was set up by Gordon McClurg, a disabled man requiring 24 hour care. It offers helpful information about independent living and can be accessed at [www.caremanagementservices.co.uk](http://www.caremanagementservices.co.uk).

## Making a complaint about care agencies

In the first instance complaints should be made to the local council or care provider. There is usually a three stage approach for complaints related to services for children and young adults:



The Local Government Ombudsman does not normally consider a complaint until it has been reviewed locally and attempts have been made to resolve the situation. Ideally, a complaint should be made within 12 months of something going wrong.

**Complaints can be made to the Local Government Ombudsman's Advice Team on 0300 061 0614 (8.30am to 5.00pm, Mondays to Fridays).**

## Care Management Services (CMS)

Care Management Services (CMS) work alongside each client to offer a care package tailored to each individual's needs and aspirations, giving greater control over how and when care is delivered. Working closely with each individual and listening to specific needs, CMS aims to provide a dedicated care team that empowers individuals to:

- live independently.
- go where they want at a time suitable to the person.
- access further or higher education.
- improve social opportunities and meet more people.
- travel at home and abroad.

Source: Care Management Service (2014) *Independent Living* [Online]  
Available from [www.caremanagementservices.co.uk](http://www.caremanagementservices.co.uk) [Accessed: 17th January 2014]

## The Enham Trust

Another similar organisation is The Enham Trust which supports people in transition towards living lives of choice, control and independence. They provide personalised care, living, learning and working opportunities. Such organisations and colleges provide advice regarding online library memberships to support learning.

## Joining a gym

*'Sport means all forms of physical activity which, through casual or organised participation aim at expressing or improving physical fitness and mental well-being forming social relationships or obtaining results in competition at all levels.'*

*Council of Europe's European Sports Charter, 1993*

The English Federation of Disabled Sport have set up the Inclusive Fitness Initiative (IFI) programme which offers disabled people more choice and opportunities to enjoy the benefits of physical activity. The key is accessibility to physical activity and there are over 400 approved facilities, with appropriate fitness equipment and gym staff trained in providing advice on adapted physical activity.

Source: English Federation of Disability Sport (2014) *IFI Gyms* [Online] Available from: [www.efds.co.uk/inclusive\\_fitness](http://www.efds.co.uk/inclusive_fitness)  
[Accessed: 18th December 2013]

## Bank accounts

Whatever type of bank account a young adult wants to open, they will need to prove their identity and (usually) their address. Examples include:

**Driving licences:** Driving licences must be valid at the time of application.

**Statements from banks and utility companies:** The statement must be an original document (not a photocopy or printout) and less than three months old unless stated otherwise.

**Utility bills:** Bills must be less than three months old unless stated otherwise.

**Documents confirming rental or ownership of a property:** A solicitor's letter confirming a recent rent agreement or house purchase can be up to six months old unless stated otherwise.

For some bank accounts, a young person can provide certified copies instead of the actual document. Discuss with the relevant bank to confirm their requirements. It is a good idea to arrange an appointment first so the young person or their advocate can explain their situation.

Source: The Money Advice Service Identity requirements for basic bank accounts [Online] Available from: [www.moneyadviceservice.org.uk](http://www.moneyadviceservice.org.uk) [Accessed: 18th December 2013]

## Benefit advice

There is a wide range of disability-related financial support, including benefits, tax credits, payments, grants and concessions, some of which have been listed below. For current information on disability allowances check out the government website: [www.gov.uk/browse/benefits/disability](http://www.gov.uk/browse/benefits/disability).

Source: Government Digital Service (2013) Disability Living Allowance (DLA) for Adults and Carer's Allowance [Online] Available from: [www.gov.uk/benefits-adviser](http://www.gov.uk/benefits-adviser) [Accessed: 18th December 2013]

**Below and overleaf are some of the available benefits:**

### → Disability Living Allowance or Personal Independence Payment

*'You can only make a new claim for Disability Living Allowance (DLA) if you're claiming for a child under 16 – this is known as DLA for children.*

*Anyone over 16 must apply for Personal Independence Payment (PIP) instead of DLA.*

*PIP is gradually replacing DLA for people aged 16 to 64, even for those with an indefinite or lifetime DLA award. Your DLA probably won't be affected until 2015 or later but there are exceptions.'*

Source: [www.gov.uk/browse/benefits/disability](http://www.gov.uk/browse/benefits/disability) [Accessed: 24th January 2014]



### → Carer's Allowance

Carer's Allowance is available to help look after someone with substantial caring needs.

The carer does not have to be related to, or live with, the person they care for. The carer must be aged 16 or over and spend at least 35 hours a week in the role of carer. Carer's Allowance is taxable and can also affect other benefits.

Source: [www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance) [Accessed: 24th January 2014]

*Continued overleaf*

## → Home and housing

Once assessed by the local council payments include:

**Direct Payment** – This enables individuals to buy in and arrange help themselves, instead of getting it directly from social services.

**Disabled Facilities Grant** – This is money towards the costs of home adaptations, to enable continued independent living.

A wealth of experienced help and advice on the funding and available support is available from organisations such as Care Management Services. The website is in the further reading section below.

## → Vehicles and transport

The Motability Scheme enables disabled people to lease a new car, scooter or powered wheelchair, using their Government funded Mobility Allowance. There are eligibility requirements.

[www.motability.co.uk/understanding-the-scheme](http://www.motability.co.uk/understanding-the-scheme)

**A disabled person can apply for the following:**

- Exemption from paying vehicle tax
- Parking benefits – Blue Badge
- Disabled persons bus pass or rail card

### **Vehicle tax exemption**

Exemption from paying vehicle tax may be available if the following apply:

- Higher rate mobility component of Disability Living Allowance (DLA)
- Enhanced rate mobility component of Personal Independence Payment (PIP)



The vehicle must be registered in the disabled person's name or their nominated driver's name. It must only be used for the disabled person's personal needs. It cannot be used by the nominated driver for their own personal use.

You must claim at a Post Office that issues tax discs if you're claiming for a particular vehicle for the first time. This cannot be carried out online or by phone.

### **Vehicle tax reduction**

A 50% reduction in the cost of vehicle tax discs is available if the PIP standard rate mobility component is awarded to the disabled person.

### **VAT relief for vehicles**

VAT relief may be available on having a vehicle adapted to suit the disabled person's requirements, or on the lease of a Motability vehicle.

### **Blue Badge scheme**

The Blue Badge scheme provides a range of parking benefits for disabled people with severe walking difficulties, who travel either as drivers or as passengers.

### **Community and public transport**

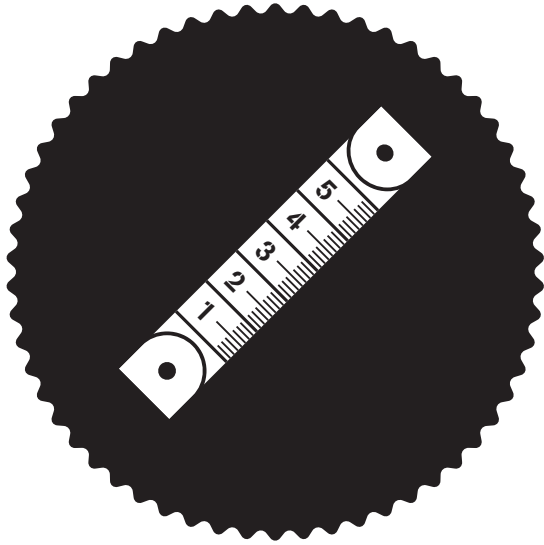
Local councils may operate dial-a-ride or taxi schemes, for example, using vouchers or tokens. Also some people may be eligible for a bus pass and/or Disabled Persons Railcard. Contact local councils to ascertain information on schemes operating in your area.

## Further reading

RESOURCE	WEB ADDRESS
<b>Article 19 of the UN Convention on the Rights of Persons with Disabilities</b>	<a href="http://www.un.org/disabilities/default.asp?id=279">www.un.org/disabilities/default.asp?id=279</a>
<b>Care Management Services</b>	<a href="http://www.caremanagementservices.co.uk">www.caremanagementservices.co.uk</a>
<b>The Motability Scheme</b>	<a href="http://www.motability.co.uk/understanding-the-scheme">www.motability.co.uk/understanding-the-scheme</a>
<b>Up-to-date benefits information</b>	<a href="http://www.gov.uk/browse/benefits/disability">www.gov.uk/browse/benefits/disability</a>







# Development

**51 “S/he’s just being a teenager!”**

**52 ACTIVITY 9**

**53 Good practice point**

**A reminder**

**ACTIVITY 10**

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**55 Good practice point**

**A reminder**

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# “S/he’s just being a teenager!”

As young people move from children’s to adult healthcare, they risk being conceptualised as either at the end of childhood or the start of adult life.

This can mean that adolescence, as a developmental period of life, can be relatively invisible from a medical perspective. In doing so, there may be limited understanding of emotional or mental well-being for young people.

There is increasing recognition that the specialist needs of young people with life-limiting conditions

differ to those of children and adults.

This section looks at the complex nature of transition exploring the move to adulthood within the context of a life-limiting illness. It explores the psychosocial development of young people and how these impact on achieving better health outcomes.

## What is ‘normal’ adolescence and why is it necessary?

The Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012) remind us that, *‘during adolescence young people expand their concept of the world, develop new cognitive capabilities and begin to question their own beliefs and those of other adults.’*

**This developmental stage is a period of continual adjustment in behaviour and may include:**

→ pushing boundaries and ignoring rules and regulations, as they don’t see where they fit within them.

→ inconsistent thought processes are common during the cancer pathway. They may fluctuate between mature and childlike behaviours depending on a particular situation.

→ responding to peer group pressure which may influence a young person’s behaviour during treatment.

→ risk-taking or experimentation without thought to consequences.

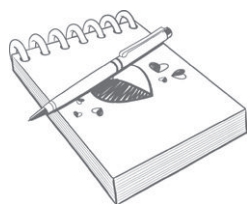
Source: Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012)

Adolescent development is characterised by physical growth, cognitive development, psychosocial and sexual development. Puberty is the transitional period during which a growth spurt occurs, secondary sexual characteristics appear and fertility is achieved. The physical changes of puberty are acknowledged as important milestones for all young people. The broader and less easily measured psychosocial aspects of adolescent development are of equal importance.

During adolescence young people develop an increasing sophistication of thought and complex logical reasoning. At the same time young people move from the position of relative dependence within the family to one of relative independence. They become individuals with a clear sense of their own identity. Peer friendships,

groups and being accepted by peers assume greater importance during adolescence. The capacity for intimate relationships develops, as does a coherent sense of sexual identity. Educational, vocational and recreational opportunities are of increasing importance.

While it is recognised that development cannot be equated with chronological age, adolescence is commonly divided into three phases: early, middle and late. Early adolescents (10-14 years) are coping with the transition from childhood. Peer relationships are a central issue to middle adolescents (15-17 years), while the transition to adult life is a major focus in late adolescence (18 years) with greater emphasis on educational and vocational goals, intimate relationships and self-identity.



## Activity 9

**Identify a young person in your care, aged between 11 and 15 years of age and taking the information that you have just read, consider the following questions:**

- ♥ Identify some of the physical changes that are taking place for your patient.
- ♥ Identify some of the emotional changes that are taking place for your patient.
- ♥ What issues do these changes present for your patient?
- ♥ How could you address these?

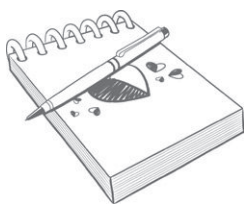
## ✓ good practice point

*'It is useful to establish 'ground rules' caring for young people and their families. Ground rules should be clear, precise and visible and should promote behavioural boundaries that are appropriate to the setting. These can outline acceptable and unacceptable behaviour, consequences of breaching local policies and address issues such as drug/alcohol use, bullying, theft and vandalism and behaviour towards staff and other patients.'*

Source: Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012)



Adolescent development does not occur in a simple co-ordinated way. For example, the young person may be tall and, to all external appearances, be an adult but they may lack emotional development. Health professionals can forget the different rates of development and run the risk of not matching their interaction to the actual level of maturity of the young person.



## Activity 10

**Reflect upon a recent interaction with a young person.**

- ♥ List any factors that may have influenced the approach you decided to take and state why.

# Growth and development

Adolescents can be very self-conscious of their developing bodies. Short stature, delayed puberty, obesity, or the visible impacts of chronic respiratory illness in terms of barrel chest deformities, clubbing, scars or indwelling intra-venous access, can contribute to poor self-image and self-esteem. This can lead to bullying, depression and anxiety (Kaltiala-Heino et al, 1999). It can also lead to the young person choosing to withdraw from peers with similar conditions.

It has also been noted that young people with chronic illness participate less in regular exercise for both health and social reasons. This lack of physical activity can then pose a problem as the young person may become more obese through lack of exercise. Conversely it has also been observed that poor nutrition and low weight is associated with chronic illness (Lazarus et al, 2000). Short stature and the delay of puberty are not an uncommon experience for young men and young women with cystic fibrosis (CF), even if they have good health (Sawyer, 2000).

## Chronic illness or disability and adolescent development

EFFECTS OF ILLNESS ON DEVELOPMENT	EFFECTS OF DEVELOPMENTAL ISSUES ON ILLNESS OR DISABILITY
<b>Biological</b> <ul style="list-style-type: none"> <li>→ Delayed puberty.</li> <li>→ Short stature.</li> <li>→ Reduced bone mass accretion.</li> </ul>	<b>Biological</b> <ul style="list-style-type: none"> <li>→ Increased caloric requirement for growth may negatively impact on disease parameters.</li> <li>→ Pubertal hormones may impact upon disease parameters.</li> </ul>
<b>Psychological</b> <ul style="list-style-type: none"> <li>→ Regressive behaviour.</li> <li>→ Adoption of sick role as personal identifier.</li> <li>→ Egocentricity persists into late adolescence.</li> <li>→ Impaired development of sense of sexual or attractive self.</li> </ul>	<b>Poor adherence and poor disease control due to:</b> <ul style="list-style-type: none"> <li>→ Poorly developed abstract thinking and planning (reduced ability to plan and prepare using abstract concepts).</li> <li>→ Difficulty in imagining the future; self-concept as being 'bullet-proof'.</li> <li>→ Exploratory (risk-taking) behaviour.</li> </ul>
<b>Social</b> <ul style="list-style-type: none"> <li>→ Reduced independence at a time when independence is normally developing.</li> <li>→ Difficulties in peer relationships.</li> <li>→ Creating new intimate (couple) relationships.</li> <li>→ Social isolation.</li> <li>→ Educational failure and then vocational failure; failure of development of independent living ability.</li> </ul>	<b>Associated health risk behaviours</b> <ul style="list-style-type: none"> <li>→ Chaotic eating habits may result in poor nutrition.</li> <li>→ Smoking, alcohol and drug use often in excess of normal population rates.</li> <li>→ Sexual risk-taking, possibly in view of realization of limited life span.</li> </ul>

Source: Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012) adapted from Michaud, Suris & Viner (2007)

## ✓ good practice point

It is important to:

1. listen to young people and reassure them that their concerns are appropriate and that you are there to support them.
2. be honest and realistic about the development of their bodies and how that may continue in the future.
3. discuss lack of options.



If you are concerned about the emotional or psychological well-being of a young person, promptly share your concerns with the rest of the team. You may wish to use clinical supervision to explore these issues further.

# Treatment and compliance

Adolescence is traditionally a time when young people begin to test things out in life and attempt to gain more independence. This is not without its complications in healthy young people but can present significant issues in young people with life-limiting or life threatening conditions.

Compliance with treatment, especially complex regimes, can be difficult to achieve for adults. It appears even more of a challenge for those going through transition from childhood into adulthood. Young people with capacity to make their own choices are likely to experience similar issues as any other adolescent trying to gain more independence. This could result in inappropriate choices or decisions. Sometimes these decisions are just too daunting to make and may be avoided.

A study by Buston and Wood (2000) looked at non-compliance amongst adolescents with asthma. 49 young people were asked if they always complied with their treatment plan, only four said that they always did. Common areas of 'lapse' included:

- forgetfulness.
- lack of confidence in the effectiveness of the medication.
- denial.
- embarrassment (not wanting to appear different).
- laziness ("couldn't be bothered").

***Most young people in this study believed their doctors were unaware of their non-compliance.***

## UNDERSTANDING THE INDIVIDUAL

**Understanding each young person as an individual, taking into account their interests, past experiences, relationships, future aspirations and coping strategies will enable teams to develop an individual care package that will support the young person.**

- It is important that all staff are consistent in their approach to care, treatment and provision of information.
- Staff should set clear and well-defined behaviour boundaries, particularly relevant to the in-patient setting.
- Cancer in a young person can result in a fundamental loss of control regarding life choices and freedom to make decisions.
- Mutual goal setting between the young person and professional helps to promote a sense of control for the young person.
- Encourage negotiation and flexibility in routine and treatment regimes where possible. This can support autonomy and may encourage compliance with treatment regimes.
- Staff should recognise the fundamental importance of young people's support networks, including family, peers and other significant relationships. Contact with their support networks should be encouraged and facilitated at all times.

*Source: Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012)*



# Risks of breakdown of care during transition

## A Senior Nurse writes about her experience:

*'Compliance with treatment is slightly different, but sometimes I feel adolescents take on the responsibility of their medication without really understanding the significance of non-compliance and how that might affect their health.*

*I cared for a young man of 18 who was outwardly very mature, but when it came to his taking his daily dose of warfarin he was considerably unreliable. Consequently his dose was always changing and he required numerous blood tests a week to try to stabilise it. After a frank discussion about his reliability and honesty he promised he would try to remember his dose and tell us if he forgot.*

*At other times I have seen younger adolescents refusing to get out of the car in hospital car parks, to avoid them having to receive their chemotherapy. When they have indwelling*



*central lines, it becomes very difficult for them to resist being connected to an infusion. But refusing to get out of the car is a method they can use to exert some control and so attempt to non-comply.*

*Even as adults some decisions and actions we take are very frightening particularly those connected with our health, so it is entirely understandable that some young people will find this sudden responsibility very challenging and may demonstrate this through non-compliance. In my experience, denial and young people not wishing to be different from their peers is an important factor in treatment compliance.'*

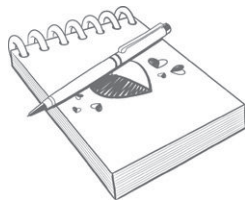
*Source: Senior Nurse, Helen & Douglas House, July 2013*

A core element of transitional care is the provision of services that reflect the changing status of the young person. This approach needs to consider the parents or guardians who are

also adjusting to a new role. The breakdown of care between child and adulthood can be very distressing and result in a loss of trust between individuals' parents and service providers.

**Transition difficulties are often multi-faceted and can occur between:**

→ child and adult services (both social and health).	→ the local authority, health services and the private and voluntary sectors.
→ primary and secondary/tertiary care.	→ young people and parents.
→ service users and service providers.	



## Activity 11

**Hannah is 16 years old and has cystic fibrosis. She is on the waiting list for a heart and lung transplant. Hannah is waiting for her GCSE results and is planning to return to school for Year 12. Her ambition is to go to university and, in order to do so, would be leaving home.**

Hannah has negotiated attending her GP appointments on her own. This has been a difficult adjustment for Hannah's parents however they recognise that Hannah has benefitted from taking responsibility for some aspects of her health. She has had a number of admissions to hospital for acute chest infections.

Using your knowledge of patients in your care and the scenario outlined above, map out the services that Hannah is likely to access.

- ♥ Identify potential areas of risk for the breakdown of transition and suggest steps that could be taken to mitigate each risk.
- ♥ Discuss how this independence may make Hannah's parents feel.

It is vital to be alert to the chances of non-compliance with treatment plans, particularly in the period of transition. This can be a time when the young person may well be experiencing a number of life changes alongside the responsibility for his or her own medication and/or treatment regime (Buston 2000).

## NON-COMPLIANCE


**Respect the young person's decisions about treatment and self-care. Explain safety issues, give them time to reflect on their decision. Reassure, listen and discuss, but remember they have a right to self-determination.**

- Advocate on the young person's behalf if necessary.
- Avoid making unnecessary demands – don't make them do things just because it is usually done that way e.g. ward routines. Enable them to decide, wherever possible, over issues such as when to get up, go to bed and have treatment.
- Explain the reasons for adherence, relative to that individual's perspective.
- Ensure treatment, where possible, fits around their lifestyle.
- Keep the young person informed at all times, making sure they are actively involved in decisions to give them a sense of power and control.
- Ensure they have positive relationships with the health professionals involved with their care.
- Encourage young people to express their concerns and foster open communication.

*Source: Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012)*

# Treatment environments

The Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012) suggest that clinical services 'provide a "home-from-home" environment for young people' as identified below.


ENVIRONMENTS

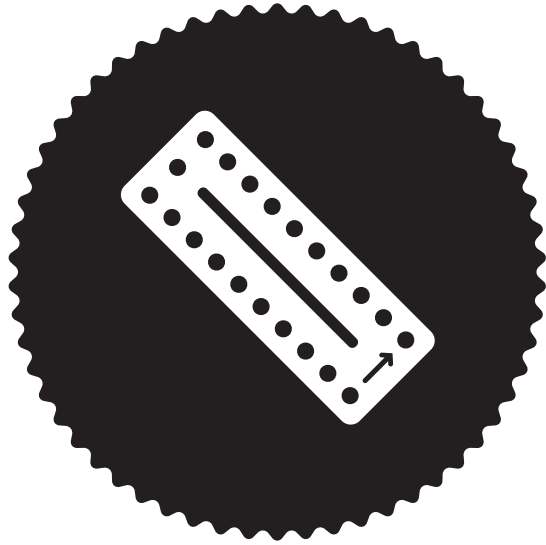
1. Personalisation of the environment. Young people can bring in personal items such as pillows, throws and photographs to individualise their bed area.
2. Use of mobile phones and/or laptops, which are often 'lifelines' to peers and family.

3. Flexible visiting times, including overnight stays where possible, to enable peer and family visiting.
4. Age-related routines. For example, going to bed later, waking later, eating at different times of the day.
5. Age appropriate recreational activities e.g. internet access (with appropriate regulations and restrictions), games consoles, pool tables.
6. Co-location of young people with people of a similar age range.

## Resources

RESOURCE	WEBSITE ADDRESS
The Association for Young People's Health	<a href="http://www.youngpeopleshealth.org.uk">www.youngpeopleshealth.org.uk</a>
Teenage Cancer Trust	<a href="http://www.teenagecancertrust.org">www.teenagecancertrust.org</a>





# Sex and Relationships

## **63 Sex, relationships and “doing what I want”**

### **Definitions of sexuality**

#### **65 ACTIVITY 12**

#### **ACTIVITY 13**

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## **66 Resources for sexual health information**

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### **Risk-taking**

# Sex, relationships and “doing what I want”

*‘I could see the other relationships going on... just like everybody you want to be loved and that would make me a bit low...there weren’t many girls...who were interested in a young man with disabilities.’*

*MD, age 22 talking about his time at college*

## Definitions of sexuality

Sexuality is widely recognised as complex and multidimensional.

Definitions can include the following aspects:

- |  |  |
|--|--|
| <ol style="list-style-type: none"><li>1. Self esteem.</li><li>2. Self-identity.</li><li>3. Acceptance of body image.</li><li>4. Comfort with gender identity.</li><li>5. Need for touch.</li><li>6. Interest in sexual activity.</li></ol> | <ol style="list-style-type: none"><li>7. Ability to communicate sexual needs.</li><li>8. Expression of caring.</li><li>9. Giving and receiving of pleasure.</li><li>10. Ability to engage in satisfying sexual activity.</li></ol> |
|--|--|



***Sexuality is integral to a person's identity and develops throughout life, from birth to death. A person's sexuality is influenced by their experiences and social, emotional, physical, cultural, economic and political factors.***

***It is natural for people across all ages to express their sexuality through their behaviour. Sexual behaviour may be expressed in a variety of ways, including language, touch, exploring one's own body or another's, sexual activity, games and interactions, and everyone has the right to express their sexuality.***

Royal College of Nursing (2014)

When focussing on disease control and management, it can be easy to overlook or downplay the importance of sexual and reproductive health issues for young people. Sexuality, relationships and reproductive health are significant issues for all adolescents and they are no less important for those with life-limiting conditions.

Young people are usually interested to learn how their body will change and develop during puberty and may spend time talking with friends. Young people with life-limiting conditions may not have the same social networks with their peers, or find it more difficult to express their feelings. They will need information to understand their feelings and desires, develop an acceptance of their physical appearance and acquire skills to form intimate relationships.

Many things can prevent a young person with life-limiting illness achieving sexual and emotional fulfilment. This could include social and cultural prejudices, professional and parental attitudes, lack of social opportunities and the lack of appropriate services. In Oxfordshire there is a project called *Mates 'n' Dates* that is set up for people with learning disabilities.

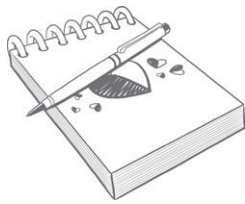
As a healthcare professional, helping young people to explore relationships is a good starting point. Young people may not choose to volunteer much information initially. Raising this topic without overt embarrassment assists the young person to ask questions at a later date, when they may feel more at ease. Choose a colleague to work with and using the PLISSIT Model below to discuss how you would approach the following three activities.

#### **PLISSIT Model**

<b>P</b>	Obtaining <b>Permission</b> from the client to initiate sexual discussion
<b>LI</b>	Providing the <b>Limited Information</b> needed to function sexually
<b>SS</b>	Giving <b>Specific Suggestions</b> for the individual to proceed with sexual relations
<b>IT</b>	Providing <b>Intensive Therapy</b> surrounding the issues of sexuality for that client

Source: Annon, J. (1976)





## Activity 12

**You are in Lucy's room assisting her to dress. Lucy seems quite excited and happy and you comment upon this to her. Lucy smiles and tells you that she has a boyfriend, Jordan.**

Jordan is in the sixth form at school. Lucy tells you that she is the only person in her year that has a boyfriend in the sixth form. She shows you the card that Jordan gave her for her 15th birthday. Lucy has some cognitive and emotional development delay. Her parents have recently split up and she has had some additional time for respite care to enable her parents to manage the adjustment required to their relationship.

- ♥ What conversation would you have with Lucy?
- ♥ How would you record the conversation in her notes?



## Activity 13

**Katherine is a 28 year old with early onset adult Huntington's.**

She has used internet chat rooms to chat to other women and recently met someone she really likes. They have regular conversations online but would like to meet in person. Katherine needs support to go out due to her declining mobility. She is worried about telling her family and friends she is gay.

- ♥ What conversation would you have with Katherine?



## Activity 14

**Ben is 19 years old and has Duchenne Muscular Dystrophy.**

During his last stay in his local hospice he mentioned to a member of the team that he would like to masturbate. However, he does not have any opportunity at home and wants to know how he can be supported to do this.

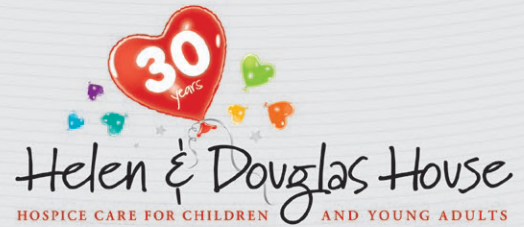
- ♥ What conversation would you have with Ben?

## Resources for sexual health information

RESOURCE	INFORMATION	CONTACT INFORMATION
<b>BodySense</b>	For young people with learning disabilities to explore aspects of personal, social and sex education, including practical visual guide to sanitary protection for young women dealing with their periods.	<a href="http://www.bodysense.org.uk/SREResources.shtml">www.bodysense.org.uk/SREResources.shtml</a>
<b>Contact a Family</b>	<p><i>Growing Up, Sex and Relationships: a Booklet for Young Disabled People</i></p> <p>There are two booklets that go with this leaflet for parents and teachers.</p> <p><b>For parents:</b> <i>Growing up, Sex and Relationships: A Booklet to Support Parents of Young Disabled People</i></p> <p><b>For teachers:</b> <i>Sex and Relationship Education for Young People with Physical Disabilities: A Booklet for Teachers</i></p> <p>The books for parents and teachers have been developed to help them understand more about some of the things that are important to young people learning about sex and relationships. Copies of this leaflet and the others are available free of charge from Contact a Family.</p>	<p><a href="http://www.cafamily.org.uk/media/379646/growingupsexrelyoungpeople.pdf">www.cafamily.org.uk/media/379646/growingupsexrelyoungpeople.pdf</a></p> <p><a href="http://www.cafamily.org.uk/media/379598/growingupsexrelparents.pdf">www.cafamily.org.uk/media/379598/growingupsexrelparents.pdf</a></p> <p><a href="http://www.cafamily.org.uk/media/379567/growingupsexrelteachers.pdf">www.cafamily.org.uk/media/379567/growingupsexrelteachers.pdf</a></p> <p><b>E:</b> <a href="mailto:helpline@cafamily.org.uk">helpline@cafamily.org.uk</a></p>
<b>Dating and friendship (Oxfordshire based)</b>		
<b>Mates 'n' Dates &amp; Mingle</b>	These services are available for heterosexual, gay, lesbian, bisexual and transgender people over 18 years old.	<p>Guideposts Trust Independent Living Centre Northfield Farm Lane, Madley Park, Witney, Oxon OX28 1UD <b>T:</b> 01993 899987</p>
<i>Also contact:</i>		
<b>The London Lesbian and Gay Switchboard</b>		<b>T:</b> 020 7837 7324
<b>Beaumont Society</b> (for transgender support)		<b>T:</b> 01582 41220
<b>Family Planning Association</b>	<p>The family planning association provides a number of practical resources for schools and parents working with young people with learning disabilities.</p> <p><i>Talking Together About Sex and Relationships</i></p> <p><i>Talking Together About Contraception</i></p> <p><i>Talking Together About Growing Up</i></p>	<p><a href="http://www.fpa.org.uk/professionals/publicationsandresources/peoplewithlearningdisabilities/talkingtogetheraboutsexandrelationships">www.fpa.org.uk/professionals/publicationsandresources/peoplewithlearningdisabilities/talkingtogetheraboutsexandrelationships</a></p> <p><a href="http://www.fpa.org.uk/professionals/publicationsandresources/peoplewithlearningdisabilities/talkingtogetheraboutsexandrelationships">www.fpa.org.uk/professionals/publicationsandresources/peoplewithlearningdisabilities/talkingtogetheraboutsexandrelationships</a></p> <p><a href="http://www.fpa.org.uk/professionals/publicationsandresources/peoplewithlearningdisabilities/talkingtogetheraboutsexandrelationships">www.fpa.org.uk/professionals/publicationsandresources/peoplewithlearningdisabilities/talkingtogetheraboutsexandrelationships</a></p>
<b>Macmillan Cancer Care</b>	Relationships, sex and fertility for young people affected by cancer.	<a href="http://be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC11679RelationshipssexfertilityE42012.pdf">http://be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC11679RelationshipssexfertilityE42012.pdf</a>
<b>NHS Choices</b>	Student sexual health. This site has advice about safer sex and avoiding sexually transmitted infections.	<a href="http://www.nhs.uk/livewell/studenthealth/pages/sexualhealth.aspx">www.nhs.uk/livewell/studenthealth/pages/sexualhealth.aspx</a>



# Sexuality: Navigating Issues of Sexuality in Palliative Care



## Who are we and what do we do?

**Helen & Douglas House** has the time and expertise to care for children and young adults with life-shortening conditions and support their families. The two hospice houses offer specialist symptom and pain management, medically-supported short breaks and end-of-life care, as well as counselling and practical support for the whole family.

**Helen House** opened in 1982 as the world's first children's hospice. **Douglas House** opened in 2004 as the world's first hospice specifically for young adults aged 16-35.

## Definitions: recognising the extent of the term sexuality

In 2006 the World Health Organisation defined sexuality as:

*"A central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors"* (WHO 2006)

## Guiding principles

Within a holistic approach to care it is necessary to consider an individual's sexuality, which has been legitimised as an important element of nursing care. In order to support young people's sexuality safely and appropriately, organisations need to develop a policy to guide their staff in how to address and respond to young people's needs. This should include what is expected from staff, and what is appropriate or not for specific areas of care, staff support and training provision, and tools to facilitate this work, for example guidance for completing a sexuality care plan with consideration of documenting and storing sensitive information confidentially.

## Things to consider for care planning

Privacy, consent, risk assessment, health education, empowerment, assumptions, culture, values, beliefs, prejudices, influences, counselling, confidentiality and trust, stigma and taboo, and legal and ethical issues (RCN 2004).

## A model for addressing sexuality during discussions with patients and responding to their needs: PLISSIT (Annon 1976)

- P** Give **PERMISSION** for people to talk to you about their sexuality, and develop this culture within your care environment
- LI** Offer **LIMITED INFORMATION** from the knowledge you have, for example about the effects of specific conditions or medication on sexual function, fertility, or body image
- SS** Seek **SPECIFIC SUGGESTIONS** from a professional with more in depth training and expertise about particular issues
- IT** Make a specialist referral for **INTENSIVE THERAPY**

## REFERENCES

Annon (1976) The P-LI-SS-IT model: a proposed conceptual scheme for behavioural treatment for sexual problems. *Journal of Sex Therapy* Today 2 pp.21-15 cited in: Heath H & White I (eds) *The challenge of Sexuality in Health Care*. Oxford: Blackwell Science Ltd.  
RCN (2000) *Sexuality and Sexual Health in Nursing Practice*. London: Royal College of Nursing  
World Health Organisation (2006) *Defining Sexual Health: Report of a technical consultation on sexual health*. Available at [http://www.who.int/reproductivehealth/topics/gender\\_rights/defining\\_sexual\\_health.pdf](http://www.who.int/reproductivehealth/topics/gender_rights/defining_sexual_health.pdf) (accessed 2/10/12)

## OTHER USEFUL RESOURCES

Barnes I (2009) WISH 143 Available at <http://www.bbc.co.uk/filmmnetwork/films/p00bjp8d> (accessed 2/10/12)  
Brandenburg D, Grover L and Quinn B (2010) *Intimacy and Sexuality for Cancer Patients and their Partners*. London: Sexual Advice Association  
Gibson F and Kelly D (2008) (Eds) *Cancer Care for Children and Young Adults*. Oxford: Blackwell Publishing Ltd.  
Grinyer A (2002) *Cancer In Young Adults through parents' eyes*. Buckingham: Open University Press.  
Macmillan Cancer Support (2012) *Relationships, Sex and Fertility*. Available at <http://www.macmillan.org.uk/Cancerinformation/teensandyoungadults/Relationships,sexandfertility/Relationships,sexandfertility.aspx> (accessed 2/10/12)

**Author:** Laura Klepping, Registered Nurse **Email:** [lklepping@helenanddouglas.org.uk](mailto:lklepping@helenanddouglas.org.uk)

## Sexuality link role – possible strategies for developing this role within your organisation:

- Gather a bank of useful resources, including articles of interest, information about local facilities (sexual health clinics, dating agencies), useful websites and books.
- Network with external agencies, local and national, to establish the expertise that exists in this area, and how you can use this within your work environment.
- Form a sexuality group working party to lead on supporting the team with issues relating to sexuality.
- Develop a sexuality policy, ensuring it is relevant, usable and up-to-date.
- Foster a culture of open communication in order to: 1. enable patients to seek support 2. enable staff to know how to provide support, and what to do if they are unsure or need additional advice in addressing an issue, and 3. allow for learning and reflection within the team.
- Seek feedback from patients about what support they would want to be available within your service provision.
- Source or develop training for the team relating to issues that are pertinent to your organisation.

## Examples

- 1 Change in appearance – dealing with weight gain, hair loss
- 2 Changing body image and the impact on self esteem
- 3 Moving back in with parents and depending on them for help
- 4 Being a parent and losing the ability to look after your children and their future without you
- 5 Fertility issues, including losing the opportunity to be a parent
- 6 Media portrayal of illnesses and personal issues
- 7 Physical changes to sexual organs as a result of condition, and how this can affect the ability to give or receive sexual pleasure
- 8 Libido changes as a result of treatment and medication
- 9 Relationships – affected by stress
- 10 Difficulties in communicating personal anxieties
- 11 Embarrassment about raising issues
- 12 Change of role within existing relationship – accepting physical care from a partner
- 13 Loss of social opportunities for sexual experiences
- 14 Loss of social opportunities for peer support
- 15 Loss of time to develop a sexual identity

# Dilemmas for professionals

In this section you will have the opportunity to consider some of the dilemmas when working with young people who wish to explore risk-taking behaviours. The learning activities are designed to explore a number of different aspects of care, including the legal and ethical issues, professional boundaries and supporting young people.

Risk-taking behaviour is an inherent part of adolescent development, although not all young people will choose to participate. The range of risk-taking will vary for each young person and can include challenging parental authority such as 'back chat' at one end of

the spectrum to the consumption of alcohol, illegal drugs and early sexual experimentation. This is a normal part of human development and is characterised by a move from behaviour that is moderated through the oversight of an adult i.e. parent and child; to one where the individual has adult status and is responsible for regulating their own behaviour.

There are a range of websites aimed at parents and teenagers in the UK. If you wish to understand more about the physiological changes that characterise adolescent development from 10-20 years old follow this link: [www.wccf.org/pdf/dahl.pdf](http://www.wccf.org/pdf/dahl.pdf)

## Resources

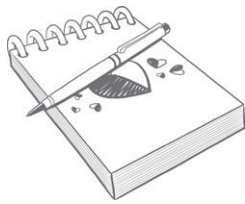
RESOURCE	WEBSITE ADDRESS
Teenage Health Freak	<a href="http://teenagehealthfreak.com">http://teenagehealthfreak.com</a>
Net Doctor	<a href="http://www.netdoctor.co.uk/womenshealth/facts/teenagerisk.htm">www.netdoctor.co.uk/womenshealth/facts/teenagerisk.htm</a>

In order to achieve clarity and aid decision-making, the following principles have been developed by Helen & Douglas House, to be applied when there are requests for potentially contentious activities from any young adult:

- **Is the activity legal?**  
Would agreeing to this request break any civil or criminal laws?
- **Where would the activity take place?**  
There may be more restrictions for activities 'in-house' than for trips out.
- **Who would be responsible for arranging the activity?**  
No member of staff should be obliged to participate in any action that offends their personal values or beliefs.
- **Who will pay for the activity?**  
Charity money may not be used for funding activities that could be deemed to be inappropriate.
- **Could the activity cause offence?**  
To other young adults or families, or members of staff.

Source: Helen & Douglas House (2012)





## Activity 15

Using the guidance on page 64, consider the following activity.

David is 17 years old. He approaches you for your assistance. He attends college and is a confident individual, able to participate in social and educational activities. David tells you that he would like to smoke and wants to try cannabis. He asks you to help him.

- ♥ Write down some ideas of the conversation you may have with David.
- ♥ How will you address the health, ethical and legal dilemmas?

Everyone working with children, young people and vulnerable adults has a responsibility to protect and safeguard those in their care. Helen & Douglas House has a *Safeguarding and Child Protection Policy* which describes the responsibilities of staff and the steps to be undertaken if there are any concerns about the safety and well-being of children and young people.

You may also wish to review your code of conduct and advice from your professional body:

- Health and Care professionals [www.hpc-uk.org](http://www.hpc-uk.org)
- Nurses [www.nmc-uk.org](http://www.nmc-uk.org)
- Doctors [www.gmc-uk.org](http://www.gmc-uk.org)

## RISK-TAKING

**It is important to assess the presence of risk-taking behaviour prior to commencing treatment. Screening tools should be used as part of holistic patient assessment.**

- Staff treating young people with cancer should be aware of the signs and symptoms that indicate participation in risk-taking behaviour.
- Young people should be encouraged to discuss risk-taking behaviour with staff in order to identify potential problems. However remember, young people may choose not to disclose risk-taking.
- Ensure confidentiality is respected if appropriate. However, inform the young person that information may be disclosed on a need to know basis if it is in the best interests of the patient to involve other staff members.
- Promote and advocate healthy lifestyle choices, whilst remaining supportive and non-judgemental should young people participate in risk-taking behaviour.
- A local conduct and operational policy should be in place to ensure young people are aware of boundaries whilst in hospital and staff are supported to challenge risk-taking behaviour within the hospital environment.

Source: Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012)





# Well-Being

**73 Emotional and mental well-being**

**74 ACTIVITY 16**

**75 Privacy and dignity**

**76 The importance of leaving a legacy**

**77 Good practice point**

**ACTIVITY 17**



# Emotional and mental well-being

## DEPRESSION AND ANXIETY

**Undiagnosed mental health difficulties in young people can lead to lower educational achievement, substance abuse, violence and poor reproductive and sexual health.**

Between 10-20% of young people in Europe are estimated to have one or more mental or behavioural problems. Mental health difficulties can potentially have a huge impact on how young people tolerate and cope with treatment. It is therefore essential that the treating team attends to their mental as well as physical health. If a young person is identified as possibly requiring input from a Mental Health Specialist, they should be referred to appropriate services as soon as possible.

*Source: Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012)*

One of the most difficult areas for teenagers to come to terms with is the emotional aspect of dealing with their illness.

Many of the children and young people in your care will be able to cope well through their own resilience. However, like the rest of the population, the ability to cope with a chronic and on-going condition can fluctuate. There are a range of unhelpful coping mechanisms that can be used such as denial, intellectualisation, regression and depression.

Denial may allow the patient to continue with a “normal” life. Young people who struggle to accept their illness may not adhere to aspects of their care, such as medication or physiotherapy. They may neglect their own self-care. As with denial, intellectualisation is an unconscious defence mechanism that allows the young

person to block out the negative aspects of the illness. This approach may not enable young people to express their emotional concerns. Regression to more childlike behaviour can be observed, which is of concern as it could increase dependence on parents and interfere with achieving independence.

Depression and anxiety are common psychological disorders in childhood and adolescence. Features of depression occur frequently in chronic illness. Young people with life-limiting conditions are more likely to have a lower level of emotional well-being than otherwise healthy young people.

## Symptoms of depression can include:

- lack of interest in normal activities.
- sleeplessness.
- low mood.
- feeling worried and upset.
- physically feeling shaky, nauseous or faint.
- withdrawal.
- having suicidal thoughts.

- self-harming.
- inability to enjoy usual interests and avoidance of usual activities.
- finding it difficult to concentrate.
- not wanting to see family and friends.
- having unexplained aches and pains.
- eating less or more than usual.
- problems sleeping.

In young people depression can manifest itself as misbehaving, school failure and risk-taking behaviour such as sexual promiscuity, alcohol or drug misuse and poor behaviour alongside the recognised symptoms of low mood, irritability, aggression, sleep and eating disturbances. The Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) point out

that young people are not always keen seek professional help which can hamper effective treatment. They therefore advise that on-going assessments are carried out for those who have a life-limiting condition. While antidepressants may be indicated, it is more common for depression and anxiety to be resolved with supportive counselling.



## Activity 16

**Joe is 15 years old and has been known to your service for the last five years.**

He is known as a lively, happy and sometimes cheeky young man who has always strived to be independent wherever possible. He attends his local secondary school and is anticipating doing his GCSEs in a few months.

On this admission you notice that Joe does not appear to be happy and sits quietly. He is compliant with his care but rarely makes eye contact with you.

- ♥ Consider the information that you have been reading in this toolkit. What possible explanations could indicate the change that you have observed in Joe?
- ♥ What actions would you take?

# Privacy and dignity

## CONFIDENTIALITY

**Confidentiality is fundamental in ensuring that teenage and young adults receive the best possible care.**

Confidentiality between young people and their healthcare professionals is particularly important in the building and maintenance of trusting and collaborative relationships; in particular, discussing sensitive issues such as sexuality, risk-taking behaviours and mental health issues. However, it is important that these areas are explored to ensure a full assessment of the young person is made so that care can be tailored to meet individual needs.

Staff must use their professional judgement in order to make decisions on information that may remain confidential between the patient and that particular healthcare professional, whilst also identifying information that should be disclosed to other team members. The essence of patient confidentiality should be on a 'need to know' basis and have the best interests of the patient at the centre of any decisions that are made.

Patient confidentiality may be difficult to negotiate as the boundaries between the young person and their parents or carers are often blurred and ambivalent. In some circumstances, the parent receives information first in order to 'protect' the young person from receiving distressing news. The level of parental or carer involvement should be negotiated with the young person and communicated to the parents.

Healthcare professionals must appropriately manage complex relationships between the young person and their parents/carers whilst adhering to legal and ethical requirements relating to confidentiality and informed consent. Staff must also be honest with young people and be clear if they feel that information they have discussed should be disclosed to others in order to protect their best interests.

*Source: Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC) (2012)*

# The importance of leaving a legacy

*'I think about my passing a lot...I've done it all my life...I haven't spoken about it much with anybody else...it's not the sort of thing I can say to my family. They say, "why do you have to go on about it?"'*

MD, age 22

Young people with a life-limiting condition will vary in how they approach their own death and part of the practitioner's role will be to support them through that process. One consideration may be the desire to leave a legacy; an acknowledgement of the life of the young person. This can take a range

of different forms including the creation of a life-story book, writing and recording a song for family and friends, or making a film about the life of the young person. At Douglas House, staff have gained experience of supporting young people in using the approaches in the example below.

*'I can't remember when I became aware that it was something he wanted to do. I think there were a few incidents but I do know that he said, "I'd like to make a film one day". He wanted it to be about when he was healthier and partly to spread awareness of Duchene's, partly as something to remember him by.*

*He wanted to watch it with his family, to sit with them, show them that he'd made it and that he'd had a happy and enjoyable life, even though he'd got this condition.*

*We went to see him at home to talk about what he'd like to do, to think about what he wanted to include...really to get a rough structure, it didn't have to be precise. He wanted to include photos from his life and bits of family film of him on the beach, when he could walk... he was in the rock pools.*



*He wanted to include family members, special occasions like when he was christened, so the Vicar is in it as well because he turned up when we were filming.*

*In the end it took about five hours to film because we needed to have breaks so he could rest...when he was talking about it (the end of his life) he got a bit upset and turned away. I almost choked up... it was emotional.*

*In the end he had a DVD and it had film and photos in it and he did watch it with his family.'*

*Source: Interview with Sarah, Senior Care Team Member*

## ✓ good practice point

1. Preparation is crucial to the success of the legacy. Spend time exploring with the young person their thoughts and ideas about the legacy. Ensure that notes are kept for the young person to refer to, so that they can be clear about what they wish to say.
2. Support the young person to ensure that they have all the documents, pieces of film and music to illustrate their narrative.
3. Set a completion date with the young person and adhere to it.

## Looking after yourself

It is not always possible to know how you will respond to a discussion that is about leaving a legacy. Questions of mortality, death and legacy can raise a range of emotional reactions. There may be times when a conversation about leaving a legacy does not trigger any particular

response and at others it may be distressing. Regardless of how you respond to a discussion about leaving a legacy it is worthwhile to explore the discussion with your clinical supervisor, line manager or a colleague.



### Activity 17

**Write a reflective piece on leaving a legacy. What it means to you and how you might support a young person to create their own legacy.**

## Resources

RESOURCE	CONTACT
Samaritans (24 hours)	Via Skype for UK or landline: 08457 90 90 90 Or Republic of Ireland (ROI): 1850 60 90 90





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Notes:





Helen & Douglas House  
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