



Young people: life-limiting conditions but life-enhancing choices

Pilot shadowing activity – Penarth
Learning Support Materials 1

Supported by
[www.mariecurie.org.uk/young people](http://www.mariecurie.org.uk/young%20people)
A Marie Curie Cancer Care Programme
funded by the Department of Health
designed and managed by PublicServiceWorks
www.publicserviceworks.com

© Copyright 2012 Marie Curie Cancer Care/PublicServiceWorks/Ty Hafan

Developed and designed by PublicServiceWorks, in association with Marie Curie Hospice Penarth, Ty Hafan Children's Hospice, and partners

Overview of the materials

These learning support materials, the first of two sets, have been developed for use by those taking part in a shadowing pilot during February-April 2012.

Pilot Shadowing activity

Organisers: Victoria Lidstone, Cath Thompson, Jo Hayes, Mark Taubert

Facilitator: Abyd Quinn Aziz

Instructional design: Marsaili Cameron, Sheila Marsh, Jud Stone

Page design: Garth Stewart

Contact details

For organising partners

Dr Victoria Lidstone

Email: Victoria.Lidstone@wales.nhs.uk

For PublicServiceWorks

Dr Sheila Marsh

Email: sheila@publicserviceworks.com

Preparing for shadowing

About Learning Support Materials 1

These materials have been specifically designed for use during the February-April 2012 shadowing pilot involving Marie Curie Hospice Penarth, Ty Hafan Children's Hospice, and other partners. Dovetailing with the face-to-face reflective sessions, they are intended to help both those being shadowed and those doing the shadowing to get their bearings and learn from the shadowing experience.

Working through this first set of materials will help participants build on their learning during the briefing workshop and prepare to make the most of their first shadowing day.

Learning outcomes for the materials

After working through these materials, you will be better able to:

- 1 think about the different **purposes** of shadowing, and identify ways in which taking part in this activity could **benefit** yourself and others
- 2 **reflect** on your thoughts and feelings so as to focus most effectively on the shadowing task ahead
- 3 explore **different perspectives** on the support and care of young people with life-limiting conditions and their families
- 4 identify and explore **assumptions** that you may be making about the care and support of these young people and their families
- 5 identify **key sources of information and guidance** on the support and care of these young people and their families.

Planning your study

The activities in this material have been designed to help you reflect on how you learn and to develop and use a reflective diary. For some of the activities, you will need a notebook and also access to the internet.

Shadowing – what’s it all about?

The following description of job shadowing comes from a website concerned with hard commercial realities. As you’ll see, job shadowing is portrayed as having a lot to recommend it, with the potential to help those involved achieve some ambitious and complex outcomes in a relatively short period of time.

Job shadowing is actually one of the most common of all training techniques for new employees. Essentially, job shadowing involves spending a period of time with a seasoned expert, observing everything that he or she does that is related to the work that is expected to be accomplished as part of the daily routine of the job. Involving one new employee to act as the observer, and one person to function as the demonstrator, this allows the new hire a chance to get a handle of what is involved in performing the tasks associated with the work.

[One] option is to implement the job shadowing after a period of orientation in a classroom setting has taken place. With this application, the job shadowing allows the new hire to already have some background into the workings of the company, with the observation that is picked up during job shadowing building on that foundation of orientation. The combination of structured educational classes with the job observation of an employee with extensive work experience works very well in a number of settings.

The concept of job shadowing has many advantages. First, the new hire may often feel intimidated about performing tasks for the first time. By allowing the new person to job shadow a long time employee for a day or two, this can often build up the confidence of the new employee. Along with this advantage, job shadowing allows the new hire to see procedures and methods in actual situations. This can help to bring to life some of the scenarios that were outlined in the training materials, making them much more real to the new hire than they were in the safe environment of the classroom.

A third benefit of job shadowing is that the new hire often has a chance to begin building rapport with other employees, which can help to integrate him or her into the job team more quickly. Acceptance into the group can often help the new employee relax and focus on learning the best ways to get things done, rather than being apprehensive about fitting into the corporate culture.

(Source: <http://www.wisegeek.com/what-is-job-shadowing.htm>)

Clearly, not everything mentioned in this extract is relevant to the situation facing you; but you’ll probably agree that there are some interesting similarities, such as facing up to potential feelings of intimidation and building confidence and rapport with colleagues.

You may have been involved before in an activity given the name ‘shadowing’, either as the person doing the shadowing or the person being shadowed. If not, you will almost certainly have experienced either observing someone with the aim of learning from them or yourself being something of a role model for other people.

Whether you were aiming to learn yourself or enable other people to learn, as someone involved in health or social care, you may well have

been aware that significant learning involves attention to three separate, though linked, dimensions:

- **knowledge** (what do you know about effective care in this particular context that you can share with others, and on what sound evidence is your knowledge based?)
- **skills** (how are you able to use your knowledge in a practical way that improves the situation of those you are caring for?)
- **attitudes** (how do you engage those you are caring for, and your colleagues, in a way that enables them to trust you and work constructively with you?).

Activity 1

What does learning mean to you?

Taking part in this activity will help you to explore what learning has meant to you in the past, and has the potential to mean in the future.

Think of a situation, as a professional, where interaction with someone else left you with lasting 'lessons learned'. Then jot down in your notebook the key features of this interaction – who was involved in what role, for example, and what lasting benefit has been involved for you? You may find the following headings useful in structuring your thoughts.

What was the context?

Who was involved?

What did you learn, and how?

knowledge

skills

attitudes

How have you benefited in the long term?

Feedback

A wide variety of factors may have been involved in your learning experience. You'll find listed below some of the factors that people have reported to be important in successful learning through shadowing. Read through the list and make notes on which of the factors seem familiar to you, why – and which you would be interested in exploring further. If these quotations don't ring any bells for you, write down your own thoughts about what tends to make learning successful for you.

'Shadowing helped me to get rid of the gap between theory and practice. It helped me answer the question, "What does this kind of work really involve?"

'It had a bit of a shock value to me, to be honest. The environment was so different from what I was used to; I couldn't have imagined it really.'

‘I’ve now got a much clearer idea of what my colleagues do – and why they often react to situations in a different way from me.’

‘For the first time really, I started thinking about what principles are common across different care settings and client groups – and which skills are transferable’.

‘It was important to put what I had learned into practice quite soon after I’d done the shadowing. I know that everything I’d learned would have gone up in smoke if I hadn’t been in a position to use it.’

Shortly, you will move on to look at how you can use reflective practice to help prepare yourself for the shadowing experience. First, though, you may want to spend a minute or two over the following questions:

- If you’re going to be a shadower:
 - How do you think you yourself would feel about **being** shadowed? Would you feel defensive, for example, or anxious? What might you do to reassure, and develop an understanding with the person you’re going to shadow?
- If you’re going to be shadowed:
 - How do you think you yourself would feel about shadowing someone? Would you feel nervous and lacking in confidence, for example? What might you do to reassure, and develop an understanding with, the person who is going to shadow you?

What is reflective practice...?

You may already work actively towards being ‘a reflective practitioner’. Or you may have heard of the concept of reflective practice but be a bit hazy about what exactly it means. Whatever your level of exposure to the term, the likelihood is that you possess a good many of the learning skills needed for effective reflective practice.

If you already keep a reflective journal, much of the information in this section of the material may be familiar to you. Check that nothing is being said that is new to you and then move on. If you don’t keep a reflective journal, use this section to get launched on what most people find an extremely helpful approach to learning in the workplace.

Basically, reflective practice is a way of learning from your own experience and using what you learn in order to improve your standard of professional practice, whatever your professional area of work. It involves thinking about what you’ve done in the past, what you’re doing now, and what you’re going to do in the future. Carrying out reflective practice requires you to be prepared to ask yourself on a regular basis questions like:

- What am I doing?
- Why am I doing it?
- Why is this experience important?
- What have I done in the past that influences what I am doing now?
- How do I feel?
- What do I believe is right?
- What will I do differently in future?

Take, for example, the task in which you are involved at present. You haven't become involved in the pilot shadowing activity without thinking about why you want to take part. You'll have considered what's involved, weighed the time needed against other commitments and thought about what you'll get out of your involvement in the end. We think about what we have done and are doing; we consider the implications of our actions and draw conclusions. We remember what has happened; and these memories affect how we act in future.

When we put this process on a continual, thoughtful and conscious footing with the aim of informing and improving our professional practice, we are on the way to becoming reflective practitioners.

...and why should you get involved?

So, what are the main benefits of reflective practice?

All health and social care professionals have important and distinctive skills to offer. Practitioners caring for people with life-limiting conditions have a particularly important role to play in building trusting relationships. If practitioners are to be able to offer such skills to people across the age spectrum, including young adults, they need to commit themselves to continuing professional development. This involves demonstrating clearly that they are not mere technicians or deliverers of prescribed treatments but thinking, caring, responsive professionals.

Activity 2

Improving practice in working with young adults

Working through this Activity will help you to identify some of the main benefits of reflective practice. It also enables you to explore the relevance of these benefits to work with young people with life-limiting or life-threatening conditions.

In the first column of the chart below is a list of general benefits associated with reflective practice. How might these be translated into specific benefits for practitioners working with young people with life-limiting conditions? Note down your suggestions in the second column.

A couple of examples have been included here to get you started. Don't worry too much if you only have a few ideas at this stage; you may want to return to this Activity during one of the sessions following your shadowing days.

Reflective practice will help you to	Relevance to young people with life-limiting conditions and practitioners
Transfer skills from one context to another	As a specialist in adult palliative care, I'm used to multidisciplinary working, where we meet to discuss where we need to go, who takes the lead in what, and how we manage. My impression is that the team looking after children is often much smaller; but as young people grow up, they need many different kinds of help, so I think my collaborative skills could be useful.
Analyse, discuss, evaluate and change your practice as appropriate	I've become conscious that, perhaps because I'm used to working with adults, I've not paid enough attention to the importance of the family unit to young adults. So I need to find ways of engaging with parents in a really constructive way.

Reflective practice will help you to	Relevance to young people with life-limiting conditions and practitioners
Transfer skills from one context to another	
Analyse, discuss, evaluate and change your practice as appropriate	
Link theory with practice, including the practical application of research	
Collect information in order to be able to take a more active role in problem solving and decision making	
Identify the ideas and beliefs that underpin your practice so that you maintain a sense of vision	
Recognise how practice can be affected by personal views	
Think through and discuss the moral and ethical issues implicit in what you do	

Feedback

The relevance of some benefits probably sprang to mind at once; others you may have struggled over. In the end, the benefits will, to a certain extent, be personal and dependent on the individual situation. You will probably agree, though, that overall ‘pluses’ of the reflective approach include the increased ability to make your caring skills visible, to take responsibility within your professional role, and to value yourself more appropriately.

Try to find time to discuss your responses with colleagues. Can they think of possible areas of relevance that haven’t occurred to you? You may want to return to your notes after your shadowing day(s) to see if and how your thoughts have changed and developed.

Of course, thinking in general terms about reflective practice is one (useful) thing. Doing it for real, with attention to structure and method, is quite another. The following Activity will help you to get to grips with one of the main tools of reflective practice – the reflective diary.

Activity 3**Design and start to use your reflective diary**

A diary is one of the main tools available to the reflective practitioner. It encourages capturing both feeling and thought, and is valuable from both short-term and long-term perspectives.

Between the briefing workshop of the shadowing pilot and your reflective session after shadowing, you will need to:

- create and start using a reflective diary – this task is designed to help you get underway so that you can capture key elements of the first day you spend shadowing.
- be prepared to share your experiences of writing and using a reflective diary with your colleagues during the reflective session

Over the next days and weeks, reflect on:

- what you heard and experienced during the briefing workshop
- what you observed, heard, thought and felt during shadowing
- particular work situations that seem significant to you in the context of this pilot shadowing activity.

Useful prompts for reflection might include:

- How was I able to contribute to my own learning?
- How did I contribute to others’ learning?
- How did I block my own learning?
- Did I do anything that may have blocked others’ learning?

- Was I prepared to be taken aback at times by my strength of feeling in reaction to what I saw or heard?
- What support was I able to call on if I wanted help in processing these feelings?
- What risks am I consciously avoiding in this situation?
- What change of feeling or shift in point of view do I perceive in myself, if any?
- What changes, if any, do I see in others?
- What requests or demands would I like to make of the people involved?
- Where was the power in the situation I was part of?
- What do I feel about my own power in this situation?
- What causes me anxiety now? How can I deal with that?
- What opportunities does experiencing this situation offer me now?
- How might I take full advantage of them?
- How might I (without meaning to) prevent myself from seizing this opportunity?

In the course of the shadowing activity, you will be learning more about the methods and processes associated with reflective practice. Some suggestions for further reading are listed in the final section of this material. Bear in mind as you explore the area further that reflective practice is by no means an easy option: it demands energy, honesty and a willingness to develop your critical thinking skills.

Transition from children’s to adult services – some different perspectives

A researcher asked an experienced children’s social worker: ‘What is the process of transition like for young people with life-limiting conditions and their families as they move from children’s to adult services?’ The social worker replied:

‘Process? Transition? It’s more like falling off a cliff...’

An evidence-gathering study carried out in 2011 confirmed the findings of other organisations active in the field – and the day-by-day experience of young people and their families – that, as they get older, many young people and their families feel let down by the level and type of support they receive.

Activity 4**Transition: exploring the challenges**

Working through this Activity will enable you to explore how you can use these findings to get the most out of your experience of shadowing.

Read the booklet, *Making the Most of Life*, which you were given at the briefing workshop. (You can also find it online at: <http://www.mariecurie.org.uk/youngpeople?Tab=3>). This summarises the findings of the report mentioned above. You may also want to follow up a weblink on the inside cover to a video in which professionals talk about their work with young people. If you want more detail on the findings, follow the weblink provided to the full report.

As you read, have the following questions in mind and make notes in response.

- (a) What struck you about the format of the summary? Did it surprise you, and, if so, why? Any implications for what you will be looking for in your experience of shadowing?
- (b) What, if anything, struck you about the findings of the study? How might you follow up these insights in your shadowing?
- (c) The summary states that, as well as interviewing young people and their families, the researchers spoke to people who pay for and design and run the services that are important for this group of young people and their families. Doctors, nurses and social workers are given a specific mention. Which other occupations or services are likely to be important in working with these young people and their families to create the support they need to live as normal a life as possible?

Feedback

You'll probably have come to the conclusion, quite rightly, that there are no cut-and-dried, right-and-wrong answers to the questions posed above. But you may find it helpful to compare your thoughts with those given below. Are there points that you would like to pick up on and incorporate into your own notes? If so, go right ahead and do that!

- (a) It's possible that you expected to see a formal brief or 'executive summary', the kind of communication that professionals are accustomed to exchanging with each other, where there is a shared language and approach. In this case, you may have been taken aback by a graphic, illustrated overview that uses humour to make the most of often searing quotations from interview. But, even if you were initially surprised, you probably soon got round to thinking about the value of an approach that does exactly what was being called for by the young people involved – positioning them in the centre of their life and care.
- (b) There are endless possibilities here... You may find one example thought-provoking as it relates to the real difficulties that can be found in doing what sounds so easy: positioning young people at the centre

of their life and care. Look at the illustration on page 6 of the summary – the heading is ‘You told us...’ The young person at the centre of the illustration is out of sight but is expressing distress about having a syringe driver: ‘The syringe driver is a machine attached to me. It’s not cool. ... I don’t look good.’ It’s possible that, in the circumstances of a life-limiting condition, you think it rather frivolous to be thinking of what looks ‘cool’ or not? But think again – in particular, think of young adults that you know. Are they not very much aware of body image, and of what’s cool and not? Overcome by embarrassment one moment, wildly exhilarated the next, nearly always hyper-conscious of the opinions of their peers? So, why would other young people be different in their aspirations and attitudes? You may find it interesting to know the story behind the quotation. The young person concerned, newly transferred to an adult hospice, couldn’t bear to have a syringe driver. The staff at the hospice told her, in short, ‘This is how we do things here; you’re going to have to get used to it.’ ‘No way’, she said, and refused the treatment. Result was stalemate; distress all round; and continuing acute pain for the young person. Take a moment to consider: how might you have responded in this situation?

- (c) Your list may include physiotherapists, who play an extremely important role in keeping stable many young people with life-limiting conditions; but you may not be aware that moving from children’s to adult physiotherapy can be a very difficult journey, with little support provided. And how many non-clinical services have you mentioned? Education offers a lifeline for many young people in this group, enabling social networking as well as intellectual development. But, whatever level of education is achieved, there is eventually an age-related cut-off point – and after that it seems to many young people and their families that there is little possibility of living a ‘normal life’ that includes training and employment and being able to see your friends. Housing officials also often have a major role to play. Consider the following comments from an experienced adviser to young people and their families: ‘*As young people grow up – get bigger! – the family might have to have a lift put in, which would take up a whole corner of the room and is very noisy, so officials have to look at the house. Can they make the bedroom and bathroom downstairs? For some of our families, it means they lose the living room. So some families’ only sitting area is the kitchen because the living room has become the young person’s bedroom and the bathroom has had to be extended as a wet room.*’ So far, only a few occupations and services have been mentioned – but, as you are likely to find out during your shadowing, many more can be involved in supporting young people and their families. It is perhaps not surprising therefore that fault lines and gaps develop among the different services; but, whatever the reasons, the effects are often devastating for those supposedly at the centre of care and support.

Exploring your assumptions

In the course of work in this pilot so far, you have probably already identified some assumptions that you carry with you about what's involved in the care and support of young people with life-limited conditions and their families.

These assumptions will link to your knowledge, skills and attitudes – these different aspects of learning discussed earlier in the material. Sometimes assumptions can involve all three aspects. Take, for example, the following assumptions identified by a senior clinician as being not uncommon in those moving from providing palliative care for adults to caring for young people with life-limiting conditions and their families.

'Adult sector staff tend to think that there is no crossover, and no similarity, between the medical conditions of young people and of adults. Because the names of conditions affecting young people are often unfamiliar to adult staff, they tend to think that everything about these conditions and their effect on people will be totally unfamiliar as well. In fact, many of the conditions across age groups have a lot in common.'

Another assumption – and this one is shared by people working with adults and with children – is that palliative care is quite different as between adults and children. People working with children often believe that they are working with a superior model – more holistic, for example. But the truth is that, as palliative care has developed, the model of care for adults and children is extremely similar. The main difference is the length of time that children have with the service.'

Both those who work with adults and those who work with children often assume that the transition process is always awful, it can never go well. This way of thinking springs partly from the fact that people tend to be very caught up with destination – and there is no destination for many young people in this situation.'

Activity 5

Finding your starting point

Working through this Activity will help you to get down on paper some of the underlying thoughts and feelings that you are bringing with you into shadowing.

In your notebook, jot down what you think are your main assumptions about working with young people with life-limiting conditions and their families. Use the headings 'knowledge', 'skills' and 'attitudes' if you find them helpful. Also, if you find it helpful to do so, use the common assumptions outlined in the quotations above as a starting point for your notes on your own assumptions. Do you share some of these assumptions, for example, and, if so, how might you use the shadowing experience to help you to test them out and develop your learning further?

Feedback

You will have the opportunity to revisit your notes later in the reflective sessions following your shadowing days. Meanwhile, you are likely to find it illuminating to read through the following two accounts of life lived with life-limiting conditions. A very wide range of cognitive and physical abilities may be involved for young people in this group. As you read, reflect on key implications of this fact for the care and support that they and their families need.

A young person's perspective

The programme supporting the pilot shadowing also offers a small grants scheme for young people (<http://www.mariecurie.org.uk/youngpeople?Tab=3>).

This scheme supports initiatives designed to enable young people to lead as normal a life as possible. A panel of young adults, the majority with complex health needs, has developed the criteria for awarding the grants and is making decisions on the applications received, supported by the programme team. One panel member responded in the following way to an invitation from a colleague to create a Facebook profile.

Account 1:

Panel member – a Facebook profile

How did you get involved in the Grants Scheme?

I found out about the Grants Scheme through another organisation I am involved in. The organisation put me in contact with the programme team to find out more about what we do and what we can give to other people and I decided there and then that I wanted to be involved.

What skills do you have to be a Grant Panel Member?

Over the last 6 years I have been involved in many organisations from all round the country (e.g Disability Rights, local Coalition of Disabled People Representative, Inclusive Education Committee Member, Sporting projects). These organisations/projects have given me a huge insight into many areas we may be looking towards helping. My main area of expertise is in Disability Rights and Sport Health + Fitness and with this knowledge of these I hope to help and get others involved in these topics too. The main skills I would say I have and bring to the panel are that I am a great listener, willing to help anyone, always have something to say, always look for a positive and willing to do anything I can to benefit others.

What are your interests/hobbies?	I have many interests/hobbies and these include..... Football (Norwich City MAD!!), Powerchair Football, Socialising with friends, Clubbing, Helping others, Working, Computer Nerd stuff and many many more.....
Name an interesting fact about yourself, which many people won't know?	I once was a Cadet for a local ATC SQD with an ambition to leave and join the RAF.
What are your ambitions?	My ambition now is to complete my studies and degree, from where I am hoping to take my career down the teaching path. Once I am a qualified teacher I hope to work with young kids and give them the best start in life.
What is your motto/slogan in life?	In my life I have hit so many barriers but I always find a way through. So my motto would be - "There's always another way"
What is your proudest memory?	When I was in the ATC I was told I would never be able to fly a plane (due to being a wheelchair user). This news was really upsetting news but I used this to help prove them wrong. So I got in contact with a local flying school and started to have lessons in flying. I am now able to fly but due to insurance purposes I am not allowed to fly solo.
What super-power would you most like to have, and why?	The super-power I would most like to have would have to be the ability to control time. This way I can fit in everything I want to do and still help everyone else in the process.
<i>A parent's perspective</i>	Where young people have profound physical and cognitive impairments, the prospect of transition to adult services is alarming for many parents. The following thoughtful account was given at a local stakeholder event in Solihull in December 2011, part of the same programme that is supporting the shadowing pilot.

Account 2: Caring for Grace – a parent’s perspective

Let me introduce you to our daughter Grace.

She is a 9-year-old girl with Downs Syndrome and Cerebral Palsy.

Grace was born with Downs Syndrome. At four months of age, she was admitted to Birmingham Children’s Hospital for a PDA ligation. Unfortunately, she arrested during this procedure and suffered a severe brain injury. We took home a very different baby to the one admitted two weeks previously. Her smile had gone, she could no longer breast feed but was instead fed via a nasogastric tube. She didn’t recognise us as her parents and lost the ability to cry. Her body was stiff, she was now suffering with epilepsy and had lost all of the skills she had developed in her short four month life.

At ten months of age, Grace became poorly with recurrent chest infections and was subsequently diagnosed with Acute Myeloid Leukaemia, a form of Leukaemia that is common to children with Downs Syndrome. She was given a 30% chance of survival at this point but six months later she was in full remission and is still with us thankfully 9 years on.

The brain injury suffered by Grace was very severe and has left her in need of substantial care the most of which is provided by myself with support from Grace’s grandparents, my husband when he is not at work (ie at weekends) and respite from Acorns Children’s Hospice and Lyndon House.

Grace:

- * has no speech
- has no cognitive skills
- has limited (if any) head control
- cannot sit unsupported and is a full time wheelchair user
- has no fine or gross motor skills
- is doubly incontinent
- cannot feed herself (Grace is fed via a Gastrostomy because she has a very poor swallow reflex)
- does not always sleep soundly at night, needing to be turned at least once, and requiring medication and feed to be administered
- Is unable to play by herself and needs one-on-one input to do the simplest of things like pressing a button on a cause and effect toy.

Grace also has multi sensory impairments and benefits massively from the following activities:

- time spent in sensory rooms which provides her with much needed multi sensory stimulation
- daily massage and physiotherapy to loosen and stretch her stiff muscles
- hydrotherapy to again relax her muscles and give her the freedom to float freely without being strapped into a piece of supportive equipment.

Whilst all of the above is a lot of work, Grace is certainly worth it! She is a lovely little person to get to know beyond the disabilities. Her smile has well and truly returned, she has likes (Adele is her current favourite) and dislikes (she is not a rock fan...) just like anyone else and is not afraid to express these. She is happy and content most of the time and grumpy some of the time, and is very much loved by her family for who she is and what she can do.

Transition

Taking one day at a time was our ‘mantra’ in the early days of life with Grace, and very much helped us come to terms with the often traumatic events in her life. It is still an approach we believe in, but as life for all of us has become more stable, the more we have felt capable of planning for the future, and the need to do this.

In this regard, transition is a worrying prospect for us. In the case of children who will never lead independent or semi-independent lives, we have to ask if transition (or what we understand of the term) is relevant for them? They are unlikely to develop any further skills and will always require the same degree of one-on-one full time 24/7 care.

What concerns us is that whilst Grace’s needs won’t change, the level of service and respite on offer will once she reaches transition age. It is not clear where we can go for the level of support and assistance we have benefited from and appreciated to date. Furthermore, it is a little alarming to think that Grace will be transferred to ‘adult’ services at a later stage as an ‘adult’ environment is not suitable for someone as vulnerable as her, regardless of age.

A transition plan needs to be flexed to suit the needs of the individual. Whilst Grace’s needs are relatively close to one end of the spectrum, she is not alone, and consideration of the transition needs of people like her would be a very reassuring thing!

What are key sources of information and guidance?

Transition from children's to adult services

The ACT Transition Care Pathway: A framework for the development of integrated multi-agency care pathways for young people with life-threatening and life-limiting conditions,

<http://www.act.org.uk/page.asp?section=115§ionTitle=ACT>

ACT, Palliative Care for Young People, 13-24,

<http://www.act.org.uk/shop.asp?section=143&itemid=129&search=palliative+care+for+young+people>

Department of Health (2008) Better Care Better Lives,

<http://www.endoflifecareforadults.nhs.uk/tools/children-young-people>

Reflective practice

Ghaye, T. and Lillyman, S. (2010) Reflection: principles and practice for healthcare professionals, Dinton: Quay Books

Tsang, N. M. (1998) Re-examining reflection – a common issue of professional concern in social work, teacher and nursing education, *Journal of Interprofessional Care*, vol 12, no 1

<http://informahealthcare.com/doi/abs/10.3109/13561829809014084>