



making
a difference
for young
adult patients

research briefing

foreword

Author:

Professor Bryony Beresford, Research Director
(Children and Young Adults Team)
Social Policy Research Unit, University of York

Editors:

Dr Judith Dorrell and Katrina Kelly

ISBN: 1 898447 25 X

Published by: Together for Short Lives,
August 2013

Design:

Qube Design Associates Ltd



Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. When children are unlikely to reach adulthood, we aim to make a lifetime of difference for them and their families.

**Together for Short Lives**

4th Floor, Bridge House, 48-52 Baldwin Street,
Bristol BS1 1QB
T: 0117 989 7820
info@togetherforshortlives.org.uk
www.togetherforshortlives.org.uk

Together for Short Lives is a registered charity in England and Wales (1144022) and Scotland (SC044139) and is a company limited by guarantee (7783702).

Disclaimer

While great care has been taken care to ensure that the contents of this document are correct and up to date at the time of publishing, neither its authors nor its publishers can guarantee its correctness and completeness. The information contained in the document is intended for general use only and users should take appropriate steps to verify such information and as necessary obtain legal and/or professional advice. None of the authors or the publishers accept responsibility for any loss, damage or expense resulting from the use of this information and no actions should be taken in reliance on it without relevant professional advice.

“...these things, if they were tweaked a little bit, could make all the difference.”

Living with a significant, potentially life-limiting, health condition brings huge challenges for young adults and their families. One of these challenges is the transition from paediatric to adult care, and the shift in responsibilities around the management of the condition from the parent to the young adult themselves, which takes place around this time.

We know that transition increases the risk of deteriorations in health and loss of contact with health services. This has stimulated research and practice development work to improve transition outcomes. To date much of this has focussed on improving planning and preparation work carried out by the paediatric teams. Much less is known about the way the nature and qualities of the ‘transfer destination’ – the clinics/teams within adult health care – influence transition outcomes, and young adults’ experiences as service users.

In 2010 the Transition Partnership¹, working alongside a team of academic researchers at the University of York, was awarded funding by the Big Lottery Research Programme to address this evidence gap through the STEPP Project (Supporting health transitions for young people with life-limiting conditions: researching evidence of positive practice).

What is clear from the findings of the STEPP project is that small changes in practice can make a big difference to young adults’ experiences as health services users and day-to-day life with a significant, potentially life-limiting, health condition.

This research briefing has been published alongside a set of practice prompts. It provides an overview of the evidence behind the changes to practice recommended in the practice prompts. We hope that together, they will inform practice and service developments and encourage professionals to make those ‘ tweaks in practice’.

Professor Bryony Beresford
Research Director
(Children and Families Team)
Social Policy Research Unit
University of York

¹ The Transition Partnership is a collaboration between Together for Short Lives, Help the Hospices and the National Council for Palliative Care.



what is this briefing about?

This briefing presents key findings from a national study (the STEPP project) on health care transitions for young adults with significant, and potentially life-limiting, conditions. The STEPP project focussed particularly on practice at the 'adult end': the clinics and wards which care for young adults with significant health conditions following their transfer from paediatrics.

The project involved interviews with young adults, parents and health professionals. We have used excerpts from the interviews with young adults and parents to illustrate, and bring to life, key findings.

As well as providing a rare insight into the views and experiences of young adults themselves; it also reveals how small changes in practice, that do not cost anything, can make a real difference.

A set of practice prompts to accompany this briefing are available from www.togetherforshortlives.org.uk/steppresources. Together we hope these publications will be a useful resource for professionals working with young adult patients with significant, and potentially life-limiting, conditions and those with responsibility for supporting the transition from paediatric to adult care.

Who is this briefing for?

- Adult health care teams with young adults on their caseload
- Palliative care teams
- Ward staff
- Senior hospital managers
- Commissioners
- Transition leads in paediatric and adult health care
- Voluntary sector organisations, including condition-specific charities and hospices

This briefing should be used alongside the practice prompts:

www.togetherforshortlives.org.uk/steppresources

contents

1. about the STEPP project	6
2. young adulthood: where do parents fit in?	8
3. making the move to the adult team: what helps?	12
4. understanding parents' involvement in clinic appointments	18
5. young adults' in-patient experiences: what can we learn?	22
6. dealing with uncertainty: having and making plans	26
7. a note about parental bereavement	32
8. useful resources and contacts	36

about the STEPP project

1

The STEPP project explored the experiences of health care transitions from the perspective of young adults who have made the transfer into adult health care, their parents and the professionals involved in their care. It sought to identify 'patient-endorsed' good practice and the ways of working or systems which support such practice.

The research was conducted within six condition-management pathways. These pathways represented a range of significant, potentially life-limiting, conditions including cystic fibrosis, renal disease, degenerative neuromuscular conditions (eg Duchenne muscular dystrophy), metabolic conditions and cerebral palsy. They also represented different sorts of transfers:

- transferring to the same specialism in adult health care
- transferring to a different adult specialism
- paediatric and adult teams co-located
- transfers within and across secondary and tertiary health care settings.

The pathways selected for the project were nominated by health professionals as examples of good practice. All fulfilled criteria for good practice set out in national policy and practice guidance. The adult services in the condition-management pathways had developed their practice in some way to make it more 'young adult' friendly.

The following groups were recruited to the STEPP project: young adults, parents and health professionals, including those working in palliative care services which interfaced with the adult specialism teams. Just under 40 young adults are represented in the STEPP project, of whom 34 participated directly. In-depth semi-structured interviews were used to collect data from all participants.

young adulthood: where do parents fit in?



Introduction

Young adults are individuals in the late teenage to mid-twenties age band. It is increasingly acknowledged that young adults are not fully emotionally, physically or psychologically mature. Indeed, young adulthood can be conceived as a distinct developmental stage: they are 'emerging adults' in transition from childhood to adulthood.

This notion of 'young adulthood' has implications for the ways health professionals work with young adult patients. It also raises questions about the acceptability and appropriateness of services and care for what is, essentially, a minority group within the broader context of adult health care.

The role and involvement of parents during this period is likely to be changing and evolving. We know from general population studies that parents are increasingly involved in the lives of their adult children. Within the context of a chronic health condition, however, greater autonomy in self-management is seen as one of the goals of transition from paediatric to adult health care. There is little evidence about the role parents play in supporting young adults with significant health conditions, and how differences in parental roles impact on transition outcomes and autonomy.

Key findings

Almost all the young adults we interviewed spoke of their parents as the 'first port of call' when they had concerns about their condition, during a period of ill-health or when significant decisions needed to be made.

"She can make her own decisions about her own health. But obviously if she was struggling with it and needed my help then I'd be happy to help her. And sometimes, if she's going through a particularly difficult patch and there's things she'd worried about... then she'll ask me to come to clinic with her." (Parent)

The health condition had been a shared experience for the family from the point of diagnosis and the young adults spoke of their parents as a key source of support. A reluctance to share this aspect of their lives with peers and leaving full time education appeared partly to contribute to social isolation. Very few spoke of serious boy-girlfriend relationships which might, potentially, replace parents' role as 'first port of call'.

"I don't really make a lot of decisions myself 'cos I've got a really, really close family. We always sit and talk about stuff like this."

2

The life-limiting nature of the condition emerged as another important contextual factor in understanding patterns of parental involvement. Some interviewees described having (or observing) a near-death experience (for example, severe respiratory infection, acute renal failure). Parents, in particular, drew attention to the life-limiting nature of their child's condition during interviews. The fragility, or vulnerability, of their son or daughter's life made some parents risk averse which could, in turn, interfere with typical trajectories of achieving independence and autonomy.

The majority of parents interviewed for the STEPP project were mothers. The mother-child relationship, and the perceived ongoing responsibilities as a mother, was often referred to when the interview turned to their involvement following the transfer to adult health care and the changes that this had brought to their level of involvement. Over and above these changes was the enduring role of being the mother of that child.

"But I'm Holly's mum. I can't help worrying. That's the way I am. I think I'll always be like it, even when she leaves home." (Parent)

Implications

The differences in levels of parental involvement across a young adult's life are important to note. As with other areas of their lives, crises or concerns around their health condition led to periods of closer parental involvement. Recognising that young adults are not typically at the life stage when the supportive role that parents have played in their lives has been replaced by another significant, long-term relationship, seems to be key to understanding these dynamics. Unlike other young adults, there is the added complexity of the presence and influence of a significant, potentially life-limiting, health condition within past, present and future family dynamics.

See section three in practice prompts:
[www.togetherforshortlives.org.uk/
steppresources](http://www.togetherforshortlives.org.uk/steppresources)

"I don't really make a lot of decisions myself 'cos I've got a really, really close family. We always sit and talk about stuff like this."

making the move to the adult team: what helps?

3

Introduction

Most research on families' experiences of transition has been concerned with elements that relate to preparing for the transfer. The STEPP project took an alternative approach: we asked young adults to reflect back over the entire process of anticipating and making the move to adult health care, which offers useful new perspectives.

Importantly, we located our research in settings identified as examples of good practice in terms of transition support. This allowed us to explore young adults' views about transition support practices.

Key findings

Readiness to transfer

We asked the young adults whether, at the time of transferring from paediatric to adult health care, they felt ready for this change. There were very mixed views on this. Some recalled being keen to move into an adult health care setting, feeling that they had 'grown out' of paediatrics. The growing independence and autonomy associated with the late teenage years was identified by many as contributing to their sense of readiness.

"You're big enough and ugly enough now to start looking after yourself."

"I wasn't really too worried or anything about it. It was probably just as I was getting older that it's the time for me to like know what's going on...."

Others acknowledged that they knew they were 'ready', but were still reluctant to make the move. A further group observed they might never have felt ready and it was the move itself which 'forced' them into being ready to take on greater responsibilities in terms of managing their health care and taking the lead in consultations with health professionals.

"I didn't want to move at first. But I were nearly 19 so I had to move. And, obviously once I did, I were happy. I wouldn't, you know, change it now."

Supporting readiness to transfer

Some believed that the paediatric team had helped them feel ready to move to the adult service. Practice within paediatrics which encouraged an increasingly active involvement in clinic appointments was consistently identified as the key aspect of supporting readiness. Interestingly, work done by the paediatric team to support independence in day-to-day management of their condition was not referred to by any of the young adults as contributing to their sense of readiness to move to adult health care.

3

A few of the young adults we interviewed reported that there had been some flexibility around when the transfer happened. They appreciated having some degree of choice about when they moved across to the adult team or to delay the transfer when other things (for example, A level exams) were competing for their time and attention.

"The transition was clashing at the same time as my A levels. So they just said, take your time, it's fine."

Anticipating the move

Some of the young adults we interviewed told us that, for them, the transfer to adult health care had not been a particularly noteworthy event. In some cases this was because other changes in their lives superseded it in importance. Others portrayed it as an inevitable aspect of being a health service user to which they had paid little attention.

A larger group of interviewees spoke of the transfer to adult health care as being a more significant event. For these young adults, anxiety featured very strongly in their recollections of feelings about the move into adult health care. Some anxieties concerned practical matters, such as travelling to and finding the clinic. More significant concerns included:

- social anxieties around meeting the adult team
- whether or not they would develop a similar relationship with the adult team to that enjoyed with the paediatric team
- 'handing over' their health to a new team
- not being certain that the quality of care and expertise of the adult team would be as good as they had found in paediatrics.

"You've put your trust in [the paediatric team] for, well it were like 18 years, ...and it were a bit nerve-wracking, that you were seeing everyone brand new and that."

Occasionally, a sense of sadness or loss was also discernible, particularly where it was clear close relationships had been forged with members of the paediatric team.

"They have become good friends to me. You don't want to leave them behind. It was just the whole feeling of.... OK, am I going to get on with these people as well as I did the last people?"

Addressing young adults' concerns

Feeling adequately informed about the adult service and having the chance to visit the clinic, view facilities and meet the adult team was key to allaying anxieties.

The areas of information which the young adults recalled as being helpful were:

- details about the adult service (for example, how clinics run, in-patient facilities, contact numbers, members of staff)
- differences between the paediatric and adult teams ways of working.

Visits to the adult clinic were seen as a key source of information. Meeting members of the adult team in advance of the transfer was always reported to be a positive experience and, for many, served to alleviate their anxieties.

"yeah, I didn't feel like... isolated and lonely 'cos I already knew 'em, had built up a relationship with 'em."

"I did like it that I got to meet the team before I actually moved. ... So I knew what the team would be like... so I was less scared."

Early experiences in the adult clinic

Interviewees recalled feeling 'scared', 'intimidated', 'overwhelmed' and 'new' when they went to their first appointment with the adult team. They varied in terms of how long it took to feel comfortable with the new team.

"It didn't take very long to rebuild that trust with all the new people."

"...getting used to the new team and things like that took a bit of... took a few months."

The experiences of those who had identified themselves as not ready to transfer were variable during the early appointments with the adult team. Some had clearly found the first few appointments very difficult, whilst others found they adapted very quickly.

3

Supporting the first few adult clinic appointments

The manner and approach of staff emerged as the predominant reason young adults gave for their first few clinics appointments going as well as could be expected. Staff were typically described as friendly and helpful.

"They're friendly. So they made my ...my adult experience quite.... welcoming."

Some chose to have their parents attend the first few appointments with them. None reported that the adult team had hindered their parents' attendance or involvement in these early clinic appointments. For some it was clear that their parents' presence was a very important source of support, others welcomed their parents attending with them but had been less dependent on them.

The young adults we interviewed consistently reported that they would have liked (more) advance information which highlighted and explained differences in practice or procedures between the paediatric and adult clinics in paediatric and adult teams. This information should be provided again by the adult team during the first few appointments. This included more practical or procedural

elements as well as more significant practice such as the way the condition was monitored and/or the reporting of results. Unexplained differences could be alarming and a source of concern, especially within the context of heightened anxieties around any evidence of a deterioration in health.

"In paediatrics they measure lung function as percentage.... I think mine was like 97%, and obviously that's on a child's scale. But then when you go to an adult hospital it's a different scale so your percentage becomes lower. So I was then like 87% or something and you kind of think of it like, 'Oh god!'. That wasn't explained to me. Like I thought my lung function had gone down because it wasn't explained to me that it's on a different scale.And it was a bit of a, it was a shock, it was a bit of a shock 'cos it wasn't explained; but now we know that obviously it's fine."



Finally, a number of our interviewees mentioned being somewhat disturbed by the age of other patients at the clinic, and/or the larger volume of patients in attendance. Again, advance warning of this prior to transfer would have been welcomed.

"The only thing that was a bit uncomfortable for me was looking around and seeing a few old, you know, mainly old people....'cos I was 17/18 at the time, I was thinking, you know, 'Oh! I shouldn't be here!"

Implications

The young adults believed that readiness to transfer to adult health care was grounded in their own sense of maturity and self-confidence. Preparation work done in paediatrics to support them to assume an active role in consultations could support readiness. Sometimes young people did not feel 'ready' to be in adult services until they made the transfer to the adult team.

The transfer to adult health care raises anxieties. Providing information about the adult service, *including differences between paediatrics and adults*, and giving opportunities to visit the adult setting and meet members of the team alleviates these anxieties and promotes readiness.

Staff behaviour and practices in the adult team are a key aspect of the transition process. Young adults valued friendly and helpful staff who recognise that the first few clinic appointments can be intimidating, and differences between paediatric and adult services can be disorientating or alarming.

See section four in practice prompts:
[www.togetherforshortlives.org.uk/
steppresources](http://www.togetherforshortlives.org.uk/steppresources)

understanding parents' involvement in clinic appointments

4

Introduction

The move to adult health care represents a significant shift in approach from family-focussed practice in paediatrics to the patient-focussed approach of adult medicine. There is an expectation that the patient will be responsible for managing their condition and will be able to communicate effectively with their doctor and others in the medical team.

Transition preparation work carried out by paediatric teams seeks to prepare young people for this change, encouraging a move from passive to lead participant in consultations, with parental presence decreasing or being withdrawn at the same time.

Within adult health care, a parent's presence at clinic appointments may not be seen as a 'good thing'. However, for other groups of adult patients, the presence of a companion is not viewed as problematic. Indeed, it can be positively encouraged in certain situations. Most young adults are not yet of an age when they have a long-term, committed partner. A desire for a parent to act as their companion at clinic appointments may not, therefore, be as problematic as might initially appear.

Key findings

Parents are involved in clinic appointments in a number of ways. Patterns of involvement can change over the course of a single appointment and over time. The extent to which young adults had achieved independence in other areas of their lives did not predict parental involvement in clinic appointments. For example, some young adults had moved out of the family home and still had their parents accompany them to clinic appointments. Likewise, some young adults were living in the family home with quite high levels of dependency but went to clinic appointments on their own.

"And when he goes he'll ring me and say 'I'm out mum' and this has happened, that's happened." (Parent)

Attendance at early clinic appointments

Almost all parents had attended one or two appointments with the adult team. As well as being there to support their son or daughter, they used it to reassure themselves of the competency of the adult team. They also evaluated their son or daughter's ability to manage the demands of a consultation. Following this, some withdrew their involvement.

4

Patterns of parental involvement in clinic appointments

Present

- Nature of involvement
 - Communicator
 - Spokesperson
 - Partner
 - 'Back-up'/corroborator
 - Information-receiver
 - Emotional support
- Focus of involvement
 - young adult
 - parent's information and support needs

Not present

- Absent but aware
 - Accompanying/transporting
 - 'Priming' prior to the appointment
 - Debrief post-appointment
- Absent and unaware (not observed in our study)

"Obviously she wanted me there the first few times, to give her a bit a confidence and that. And I had to go to reassure myself... to make sure." (Parent)

Young adults' explanations for their parents' ongoing involvement

Some of the young adults we interviewed were very clear that they wanted their parents to continue attending appointments with them. Their role as communicator, information-receiver and/or supporter were highly valued, if not indispensable.

Others appeared less reliant on their parents' presence. In these instances young adults identified, and appeared to accept, that the parents' attendance was driven, at least in part, by their own needs or responsibilities as parents/carers.

Parents' explanations for continuing involvement in clinic appointments

Many of the parents who attended clinic appointments did not believe their son or daughter had sufficient understanding of their condition and/or the maturity to attend appointments on their own. Parents who had responsibility for monitoring the condition on a day-to-day basis felt they needed direct consultation with clinicians in order to fulfil this role.

For some parents, not attending appointments carried too many risks. They were concerned their child might not remember or understand information given to them. Or they were worried their son or daughter might not report changes in their health because of their desire to avoid evidence of deterioration.

Parents' re-attendance at clinic appointments

Young adults who typically went to appointments by themselves wanted the option for parents to attend to remain open. Reasons for 'recalling' their parents to consultations included: difficulties with communicating with the medical team, appointments where significant decisions were to be discussed, or concerns about their health.

Parents had also requested attendance as a 'one-off' or had re-started attending routinely. The reasons given for this more active involvement in clinic appointments were: deteriorations in the young adult's condition and/or parental concerns about the management of the condition which their son or daughter was failing to raise at appointments.

Implications

Our understanding of the role of parents in appointments being attended by young adult patients is very limited. It could be argued that practice with respect to this issue has been based on assumptions of 'the right thing to do' rather than evidence. The findings from our research suggest parental involvement in young adults' clinic appointments is a complex and dynamic topic. For example, within our sample were young adults who had 'flown the nest' and yet wanted a parent to accompany them to appointments. Equally, we had very poorly, physically disabled patients still living in the family home who were choosing to go to appointments on their own. Across these different situations, the overriding message from young adults was that they wanted to be able to choose who, and if, someone accompanied them to clinic.

young adults' in-patient experiences: what can we learn?

5

Introduction

Very little is known or understood about the experiences of young adults who are admitted to adult wards. This is, however, a key issue for young adults with significant health conditions. Some will need to adjust to planned admissions associated with the management of their condition taking place in adult, as opposed to paediatric, specialist units.

For many there is the risk of an acute exacerbation or complications resulting in unplanned admissions. Indeed, for some, the late teenage years coincide with deteriorations in the condition resulting in an increase in the number of medical emergencies.

Currently, however, preparation for being a patient on an adult ward is not usually addressed in the planning and preparation that precedes the transfer from paediatric health care.

"And, of course, it's straight in, there's no sort of halfway; it's kind of children's and adults. So it's just... yeah, quite a big leap."

Key findings

Young adults and parents consistently identified poor in-patient experiences as the most difficult aspect of the transfer to adult care. General medical or respiratory wards emerged as the most problematic setting, though similar (but typically less extreme) experiences were reported during stays in in-patient episodes in specialist centres/units.

"...it wasn't the nicest ward because there were some very ill people and it was quite scary. It's a more sterile place ...and if they're old people are likely to die. So it can be quite a depressing place. ...The children's ward is probably a better atmosphere [even if] it is a bit noisier."

"I remember thinking at the time it seemed a bit unfair that, you know, he's on this ward with a load of old people that were struggling to breathe, and it was quite frightening for him." (Parent)

Factors contributing to negative experiences

A lack of information and preparation

Families lacked information about differences to expect between children's and adult wards, such as the age and condition of other patients and restricted visiting hours.

"Everything should be explained a little bit more carefully because it is all very new, especially when you're transitioning." (Parent)

Feeling ill-prepared for the shift to an adult ward was disorientating, and often anxiety-provoking. This points to a current gap in transition planning.

"You were just booked in and then you're just left in the room by yourself, and you're thinking: 'OK, now what do we do?'. You know, you don't know the routine, you don't know when the physios are coming, you don't know when the IVs are coming, you don't know when the food is coming, you're not meant to be meandering around because of cross-infection. And you feel like you're just left and nobody's considered, actually you might both be quite nervous or scared because this is a completely new situation."

Ward staff knowledge of 'unusual' conditions

Young adults and parents reported a lack of knowledge and expertise among general medical/respiratory ward staff in terms of the young adults' health conditions. This led to distressing experiences of perceived sub-optimal care and fear that the life-threatening nature of some admissions was being overlooked.

"...it's the respiratory wards that need to be looked at; maybe the staff need a bit more training on how to deal with young lads coming through their system with these sorts of conditions. They need to be more aware of sensitivity around conditions like this."

The transfer from a general medical ward to the in-patient unit at a specialist centre typically threw the difference in expertise into sharp relief.

"... So if we can get transferred to [specialist unit], I sort of walk through the doors and go 'Ah, I can relax now.' ...I think it's the confidence that knowing that they do know what they're doing and you don't have to worry quite so much."

Assumptions about autonomy

Families found the relative 'immaturity' of young adults was often unrecognised by adult ward staff. Staff assumed the young adults could, and wanted, to make all their own treatment choices without parental support.

"I don't think you're an adult when you're 16... because at 16 years old you're still very immature and you've got no responsibility in your life and then all of a sudden they're transferring you over to an adult ward where you have to do everything yourself, basically."

This led to some very traumatic experiences, particularly when the decision being taken was highly significant and/or irreversible.

"..the decision was taken out of our hands and given to Matt who couldn't handle it... and he's there crying because he hasn't got his mum or dad with him." (Parent)

Mixed experiences of flexible visiting and overnight stays

Families reported lack of scope or inconsistencies in ward policy (and practical facilities) to accommodate parent overnight stays, despite the young adults' need for emotional and practical (personal care) support.

"[it] really wasn't appropriate for me to be sleeping on a male medical ward. All these poor old men, bless 'em, so poorly. There's me, you know, looking for, trying to access a shower or anything, was just horrendous." (Parent)

Families valued staff who would 'flex' ward policy to take account of these needs.

Social isolation

Often surrounded by much older people on an adult ward, young adults felt bored, socially isolated and lacking the support - from peers and nursing staff - they had benefitted from on children's wards.

"People maybe don't treat you in exactly the same way as they used to [on the children's ward], it's quite dark and harsh and reality hits in and you have to just get on with it. There's no... there's no flowery bits round the edges."

Furthermore, the opportunity to use social media - their main route to access support from friends - was hindered by the cost of internet or Wi-fi access.

Implications

These findings present a compelling argument for the need to improve the in-patient experience of young adults on adult wards. Three overarching issues are responsible for many of the difficult and distressing experiences described above.

- the lack of advance preparation and information for families;
- the relative 'immaturity' of young adults not being recognised in the policies and practices of wards and individual staff;
- the lack of knowledge and expertise of staff on general medical/respiratory wards in terms of the health conditions which young adults being admitted to their wards may have.

The relevance or importance of each of these issues will, naturally, vary according to the characteristics of a specific health condition and the location of the in-patient setting.

See section five in practice prompts:
www.togetherforshortlives.org.uk/stappresresources

dealing with uncertainty: having and making plans

6

Introduction

Whilst the young adults who participated in the STEPP project were not in the end stages of their condition, it became very apparent that prior to making end of life plans, there are a range of plans which young adults and their parents desire to have, including plans for managing deteriorations in the condition and medical crises.

These plans played an important role in minimising anxiety and enabling young adults to 'get on with their lives', thus supporting a good quality of life within the context of the uncertainty that comes with having a life-threatening condition.

Key findings

The importance of having plans

Having plans in place in the event of worrying symptoms or medical crises, as well as considering future treatment options, played a very important role. They prevented young adults and parents from being stifled by concerns and anxieties which can pre-occupy and drain emotional energy.

"Planning what's going to happen in the future is very important to me. So you know and you're ready... So you know what to expect and you feel very calm about it."

"It's always nice to know that if something does go wrong, there's going to be plans to help you, the best, the best plans as, as possible."

The different types of plan

Plans for managing certain symptoms or general ill-health

Knowing what to do when certain symptoms were experienced or the young adult was feeling generally unwell was very important. Almost all the young adults we interviewed had a clear plan or 'protocol' for what they should do if they were concerned about their health - ranging from self-management, to contacting the clinic, to calling for an ambulance. All found such plans very reassuring and gave them greater confidence in managing their condition.

"I'm not as nervous anymore. I feel more in control, that I can deal with a chest infection at home now. I know what signs to look for."

Plans for future treatments

For conditions where treatments or interventions to manage deteriorations were possible (for example, renal disease, cystic fibrosis), having plans related to future treatment options were also important. Depending on the stage of the disease, simply having a plan for when active decision-making would happen, and who would 'activate' the decision-making process, could be sufficient.

6

What was important was that young adults and their parents felt they had opportunities to discuss concerns, and/or knew that the clinical team would raise issues in a timely manner. Some young adults with cystic fibrosis, for example, knew that, at their clinic, a clinical marker was used to trigger discussions about lung transplants.

"No, they don't normally do that until your lung function really gets lower and don't come back up."

Plans for the management of a medical crisis

An emergency admission could be a very traumatic experience, throwing a clear spotlight on the fragility of the young adult's life. It can also be a time when rapid decisions are required in terms of treating or managing the medical crisis. All the young adults interviewed had, inevitably, had periods of ill-health and been hospitalised, but it was only the young men with Duchenne muscular dystrophy who had experienced what might be called an acute medical crisis. For all, as would be expected, this took the form of a severe respiratory illness resulting in an admission to an intensive care or high dependency unit.

In both the research sites where young men with Duchenne muscular dystrophy were treated, planning around the management of a medical crisis routinely took place. Young adults and parents valued these plans very highly. Many had prior experiences of emergency admissions which had not been covered by some form of emergency care plan: typically these had been extremely traumatic. Planning had prevented a re-occurrence of these very distressing situations.

In one site, which did not have its own in-patient facilities, emergency care plans, developed through conversations between members of the clinic team and the family, held information about the family's wishes regarding clinical management and involvement of the parents both in caring for their son whilst on the ward and in decision-making.

"So it's on his notes now that, if he's admitted, to allow us all to be at the bed no matter what the time." (Parent)

In the other site, an ambulance directive was used which meant that the young men were admitted directly to the specialist unit as opposed to a local hospital. In both sites,

difficult and very poorly managed situations in the past had led to routinely drawing up these plans. Importantly, whilst some young adults had made decisions about resuscitation and these were included in their plans, none described these as end of life plans. Rather, they were presented as plans to manage a medical crisis.

Planning for end of life

It is important to conceive planning for 'end of life' as just one element of the plans young adults (and their families) make about their health. We have already described how making and having plans for managing health concerns, deteriorations and medical crises was extremely important to young adults and their families. For many, this was all the planning they wanted to do at the stage they were with their condition: they did not perceive a need, or want, to explicitly make plans for the end of their life.

One explanation for this is that some of the young adults included in this study had conditions where the end of life phase was some time in the future. For these young adults, death was a remote possibility. However, even where the prognosis was much poorer or life expectancies markedly

shorter, some young adults were choosing to avoid addressing end of life. This may well reflect a way of coping with this aspect of their condition.

"There may be things that I'd rather not know if they did happen [referring to respiratory failure] 'cos it may be scary or... I've heard people have a few problems but they're very... they're not that common and things... we'd rather not know certain things."

There was also a sense from some young adults and parents that to admit the inevitability of death meant, for some, a loss of hope. This was not something they wanted to relinquish.

"It is a terminal illness, and I know, you know, touch wood it won't happen..."

There are, however, implications in terms of a desire, or readiness, to plan for end of life. Indeed, only a handful of young adults taking part in the STEPP project had end of life plans. In these cases, end of life planning had developed from earlier plans around the management of an acute medical crisis and health professionals had been pro-active in raising the need to make further plans.

6

All were glad and reassured that these plans were in place: a difficult conversation was out of the way, and it had generated greater openness in the family.

"You're never prepared when something like that happens, but at least the wheels will be kind of in motion and there won't be any untoward hiccups or things that makes it just more, harder. It's, it's just comforting knowing that something like that is in place, which I would say any family should do." (Parent)

"And even now, from time to time, he will talk about it. He will talk about things very sort of matter-of-factly and to the point of saying... 'Oh well I've changed my mind I don't think I want to be cremated any more'..." (Parent)

Finally, it was very clear from the interviews with some parents that, in light of their son or daughter's health, they wanted an opportunity to speak privately with the health team. It is important to address the support needs of parents who, potentially, may be the first to start raising difficult or sensitive issues.

"I don't know how to prepare her for when she gets worse, I don't. No one's spoke to me about it, you know, and it's a terminal illness.... and I know the inevitable is going to happen, but no one talks to you about it." (Parent)

Conversations relaying difficult information or about significant health decisions

Drawing on both the positive and negative experiences described to us during the interviews, it is possible to identify what contributes to good practice when having conversations with families in which 'difficult' information is being divulged and/or significant health decisions have to be made. The following principles emerge from our evidence:

- Work with a family's pattern of information-sharing and decision-making
- Identify the young adult's preferences around parental involvement
- Provide parents with the opportunity to raise issues privately
- Use trusted practitioners
- Pre-empt or avoid crisis decision-making
- Share difficult information gradually and with sensitivity
- Choose a time which minimises the 'threat' of the information or decision
- Use familiar and 'low anxiety' environments
- Record and share the family's level of knowledge/understanding of issues and decisions made.

Implications

In this section we have presented clear evidence that having plans for managing or responding to health concerns, deteriorations and medical crises plays an important role in enabling young adults and families to live their lives with minimum concern and anxiety. In many cases, these plans had been initiated, and were supported by, the clinics or units these young adults attended. In addition, health professionals emerged as playing a key role in the young adults' and parents' accounts of making these plans.

The findings regarding young adults' and parents' desires to plan for end of life are less clear cut and more complex, even to the extent that contradictory views were expressed (and acknowledged!) by individuals during the course of their interviews. We have, however, been able to present evidence on why end of life planning might be something that is not perceived as relevant to some or, equally, not something that a young adult wants to pursue.

Knowledge and understanding are central to decision-making. Our analysis of families' experiences of 'difficult' conversations and decision-making situations has identified a number of elements of good practice.

See sections six and seven in practice prompts:

www.togetherforshortlives.org.uk/steppresources

a note about parental bereavement

7

"Even though families may be told from a very early age that their child is going to die, it's an absolutely catastrophic time for them...."

The death of a young adult is always 'untimely' and an enormously significant event for parents. Bereavement support needs, together with those of other family members, should be a core element of care.

There is a growing body of evidence that demonstrates parental bereavement is a different experience to other forms of bereavement. It has also been linked to increased risks of morbidity and mortality, with its impact being observed 20 years after the death of a child.

It can be argued that parents who lose a young adult son or daughter from a chronic health condition face particular issues. The transition from paediatric to adult health care may have interrupted or delayed planning for medical crisis and/or end of life which might contribute to a 'poorly managed' death, adding to parents' distress. The death may also occur at a time of significant changes in services and support available to the family. Parents will have experienced a loss of relationship with staff in children's services and relationships with the adult team may not be well-established enough to replace this bond.

Finally, some young adults will have been the 'minority group' under the care of the adult health team. In these settings spousal, rather than parental, bereavement may be much more common. The specific needs of bereaved parents may not be recognised or staff may feel unable to respond to them. Practitioners' awareness of bereavement support services (locally and/or nationally) may be poor.

Parent bereavement support practices

Bereavement support practice in the clinics represented in the STEPP project typically included the following elements: a letter of condolence from the consultant; the offer of a 'de-brief' appointment; attendance at the funeral by the staff member in closest contact with the family. Less common were visits to the family at home and an open-ended invitation to contact the team. Very few of the staff we interviewed reported signposting or referring parents to bereavement support services. Some said they assumed parents would access support via their GP.

7

All the staff we interviewed for the STEPP project felt their efforts to support parents were insufficient to meet the considerable and longer-term needs of parents and other family members. Equally, however, they did not feel they were in a position to provide bereavement support. A lack of time, expertise and concerns about professional boundaries were the main reasons offered for this.

"I've always had major concerns about this [ie bereavement support]... [but] I don't think we'll be extending any further into that area, 'cos I'm not quite sure it's probably our place to do that."

Implications

The purpose of this short section has been to alert practitioners to the issue of bereavement support for parents whose young adult son or daughter has died. We have described the evidence suggesting parental bereavement is a unique phenomenon with long-term consequences. Evidence from the research sites taking place in the STEPP project suggests that staff in clinics may well feel they have a limited role, constrained by issues of time, lack of expertise and concerns about professional boundaries. Parents of young adults who died without the involvement of palliative care services may be particularly at risk of their needs not being recognised.

It would appear there may be scope for clinics with young adults with potentially life-limiting conditions on their caseload to develop a knowledge-base of local and national sources of bereavement support, and be more proactive in referring, or signposting, parents to these services.

See section nine in practice prompts:
[www.togetherforshortlives.org.uk/
steppresources](http://www.togetherforshortlives.org.uk/steppresources)

"All the staff we interviewed for the STEPP project felt their efforts to support parents were insufficient to meet the considerable and longer-term needs of parents and other family members."

resources and useful contacts

8

Palliative Care Organisations

Together for Short Lives

Together for Short Lives is the UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including children's hospices. Our work helps to ensure that children and young people can get the best possible care, wherever and whenever they need it.

Helpline: 0808 8088 100

Office: 0117 989 7820

info@togetherforshortlives.org.uk

www.togetherforshortlives.org.uk

Help the Hospices

We are the UK charity for Hospice Care. We want the very best care for everyone facing the end of life. We are here to support our members and other organisations as they strive to grow and improve end of life care throughout the UK and across the world.

Tel: 020 7520 8200

info@helpthehospices.org.uk

www.helpthehospices.org.uk

National Council for Palliative Care

We are the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition.

Tel: 020 7697 1520

enquiries@ncpc.org.uk

www.ncpc.org.uk

Bereavement Support and Services

Childhood Bereavement Network

The Childhood Bereavement Network seeks to ensure that all children and young people in the UK, together with their families and other caregivers, including professional carers, can easily access a choice of high-quality local and national information, guidance and support to enable them to manage the impact of death on their lives.

Tel: 02078436309

cbe@ncb.org.uk

www.childhoodbereavementnetwork.org.uk

Child Bereavement UK

Child Bereavement UK supports families and professionals across the UK. They provide confidential support, information and guidance to families and professionals. Professionally trained bereavement support workers are available 9am -5pm Monday to Friday.

Tel: 01494 568900

www.childbereavement.org.uk

Specific condition organisations who can offer support and information

Muscular Dystrophy

The Muscular Dystrophy Campaign

The UK charity dedicated to improving the lives of children and adults affected by muscle disease. It provides free care and support, funds research to find treatments and cures, campaigns to bring about change and awards grants towards the cost of equipment such as wheelchairs.

Helpline: 0800 652 6352

Office Line 0207 803 4800

info@muscular-dystrophy.org.uk

www.muscular-dystrophy.org.uk

Cystic Fibrosis

Cystic Fibrosis Trust

Offers support and information to anyone affected by cystic fibrosis. It funds research, offers some financial support to families and campaigns for improved services. It publishes regular newsletters and has a wide range of information available.

Helpline: 0300 373 1000

Office: 020 84647211

enquiries@cftrust.org.uk

www.cftrust.org.uk

Kidney Disease

The British Kidney Patient Association (BKPA)

The BKPA is concerned with the welfare of individual kidney patients and their families. Closely associated with the major renal units throughout the UK, where necessary it offers financial support to cover the expenses incurred as the result of the kidney condition and the costs of hospital visiting. It provides a wide range of information.

Tel: 01420 541424

info@britishkidney-pa.co.uk

www.britishkidney-pa.co.uk/grants.html

infoKID

A new information website from Royal College of Paediatrics and Child Health, for parents and carers about kidney conditions. infoKID will be an online information resource about kidney conditions in infants, children and young people. The information will cover a range of conditions, symptoms, causes, diagnosis, treatment and management. Parents and carers will be able to access content as and when they need it - to read on-screen or download as leaflets. (Due to be launched Autumn 2013)

www.rcpch.org.uk

Heart Conditions in young people

Children's Heart Federation

The Children's Heart Federation is the leading children's heart charity and direct service provider as well as the umbrella body for voluntary organisations; working to meet the needs of children and young people with congenital and acquired heart conditions and their families.

Infoline: 0808 808 5000

www.chfed.org.uk

Cancer in young people

Teenage Cancer Trust

Focuses on the needs of teenagers and young adults with cancer by building specialist teenage units in NHS hospitals. The Trust works with experts in teenage and young adult cancer care, to provide clinical expertise, develop services and research, professional education and training and represent and advocate for teenagers and their families.

Tel: 0207 612 0370

tct@teenagecancertrust.org

www.teenagecancertrust.org.uk

There are many other condition-specific support groups and charities. For further details of such organisations, please contact:

Contact a Family

Contact a Family is a national charity providing advice, information and support for any family with a disabled child, whatever the child's condition. Their helpline staff can answer queries on all aspects of raising a disabled child. They also provide a directory of over 400 condition support groups.

Helpline: 0808 808 3555

info@cafamily.org.uk

www.cafamily.org.uk

About Us

The Transition Partnership first formed in 2007 and is made up of three national charities that all have a specific interest in palliative care. The Transition Partnership aims to coordinate and steer the work of these partner organisations in their approach to transition issues relating to life-limited or life-threatened young people and their families. The Transition Partnership members are: Together for Short Lives, Help the Hospices and the National Council for Palliative Care.



THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



Acknowledgments

This guide was written and produced on behalf of the Transition Partnership with funding from the BIG Lottery Research Programme.

The Transition Partnership would like to thank all those who contributed, in particular:

Professor Bryony Beresford, Social Policy Research Unit, University of York.

Dr Judith Dorrell, Independent Consultant.

The success of the STEPP project was dependent on the willingness of young adults, parents and professionals to share their stories and experiences. We are very grateful to all those who took part, particularly the young adults who spoke with such candour and believed in sharing their stories in order to benefit others.