



making a difference for young adult patients

practice prompts: key messages from research

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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.

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about this guide

This guide is an important product of the STEPP project – a three year research study funded by the Big Lottery Fund Research Programme, looking at the transition from paediatric to adult health care for young people with life-limiting or life threatening conditions.

Key features of the project were:

- It looked at practice across different conditions and organisational settings;
- It was particularly concerned with practice within adult health care contexts in terms of supporting positive health transitions

Here we present key messages from the study – exploring direct experiences of young adult patients with life-limiting and life-threatening conditions as they move into adult health care.

It provides a unique insight into how small changes in practice can make a real difference to the experiences of young adults.

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

This guide is intended to relay the key results of the study and to provide simple advice on working with young adult patients. It will be particularly relevant for:

- clinical and non-clinical staff working in adult health care
- specialist teams caring for young adults with complex and/or life-limiting conditions
- ward staff
- senior hospital managers
- transition leads in paediatrics and adult health
- commissioners
- condition-specific charities

As a completely portable and resilient resource, it is recommended that this guide is used to provide helpful prompts for dealing with situations and questions that commonly arise when treating a young adult patient with palliative care needs.

“Maybe staff need a bit more training on how to deal with young adults coming through their system with these sorts of conditions.” (Parent)



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



who is a young adult?

Young adulthood is increasingly recognised as a **distinct developmental stage** spanning late adolescence to mid/late twenties.

Young adults are neither adolescents nor adults. Though they will have fully outgrown childhood, their brains are still developing – meaning they won't have fully attained certain characteristics that are usually associated with being an adult. For instance, their emotional and psychological maturity, as well as some key skills, will still be developing.

The term 'emerging adulthood' effectively sums up this period of ongoing transition into adulthood.

Young adults with chronic conditions diagnosed in childhood, especially those which are life-limiting or life-threatening, may well be less mature than their healthy peers.

*"I've found very much that their levels of maturity aren't the same as a healthy young person."
(Senior practitioner)*





young adults and their parents

In terms of living with a complex health condition, most young adults view their parents as their main source of support. Unlike other adults, the majority of young adults are not at the stage at which parental support has been replaced with another source of committed support, such as a long-term partner.

On a day to day basis, levels of parental involvement in young adults' lives varied enormously. However, even the most independent young adults - who were working and living in their own homes - still saw their parents as the 'first port of call' when there were health concerns, significant decisions to be made, or ill-health meant they needed looking after.

"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..."

Young adults wanted choice and control over how their parents were involved in clinic appointments and (significant) health decision-making. They didn't want health professionals to assume that their parents shouldn't be involved.

"They expected me to make a really hard decision on my own, and I wasn't sure what to say. It was only me in the room. I was on me own and they were telling me these things and I didn't know what to say."

Parents of young adults play similar roles to other people who accompany individuals to appointments, acting as: communicator, information receiver and a source of emotional support.

"...When I get out of the appointment I'll be like, like what... you know... what did the doctor say again? So I've got my mum to like, be like, right, you know. And if there's any questions to ask... if I ain't asked them me mum will."

Young adults' preferences about parental involvement are subject to change: a health crisis, difficulties communicating with the clinic team, or signs of deterioration can make young adults want their parents to be more closely involved.



"Sometimes if she's going through a particularly difficult patch and the things that she's advised she's worried about and a bit mixed up, then she'll ask me if I'll come with her so that I can understand it for her." (Parent)

Our research showed that young adults understand and respect that their parents are bound to be concerned about them. They realise that parents need to be confident in the adult team which has taken over their care.

"I still had to go to clinic the first few times and reassure myself... to make sure, you know. But now I feel right confident and I know they're looking after her well. So I've stepped back now: it's Holly's time to look after herself." (Parent)

Some said their parents need the chance to speak with the clinic team on an on-going basis.

"Parents do need to be told what's going on and what's happening because, at the end of the day, they're your family. And I'd rather the doctor tell 'em than me because at least he will tell them exactly right whereas I could forget some important things that they need to know."

"They don't completely shove me mum and dad out like. The Unit's always got time for 'em, and answers anything that's on their mind and that."

Issues for you and your team to consider

- ✓ Does your practice reflect on and respond to the reality of parents' involvement in young adults' lives?
- ✓ Do the young adults under your care feel they have free will and control over how much their parents are involved in appointments and decision-making?
- ✓ Does any of your practice work against young adults having the support they need when attending appointments and/or are faced with making difficult decisions?
- ✓ How can you provide opportunities for parents to speak with a member of the team?



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early days in the adult clinic

'Scary', 'intimidating' and 'overwhelming' were some of the words young adults used to describe their first few appointments with the adult clinic.

They recalled being worried that they wouldn't develop the same relationships with staff as they enjoyed in paediatrics. Developing relationships and trust with the new team was of paramount importance.

"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?"

Differences in the way clinic appointments/investigations were run compared to the paediatric clinic were **disempowering and caused anxiety**.

"At the paediatric clinic you get weighed without your shoes without your coat, whatever... But at the adult clinic you get weighed with your shoes on... and at paediatrics they take bloods before you see the doctor and the adult clinic after the doctor... a different routine."

"...I thought my lung function had gone down because it wasn't explained to me that they do it on a different scale in the adult clinic. It was a shock... 'cause it wasn't explained."

Some found 'taking the lead' in appointments and remembering what's been said to them very difficult.

"I don't always find it easy because I'm not used to it."

"I do struggle to retain information. I sometimes do struggle to take in everything they say in appointments and that."

In some instances, the other patients were very different to them and this was quite alarming.

"I was looking around and seeing mainly old people... 'cos I was 17/18 at the time, I was thinking, you know, 'Oh! I shouldn't be here!'"



Making a difference

- ✓ Provide opportunities for young people to meet the adult team, and visit the clinic, in advance of the move from paediatrics.
- ✓ Make sure the information for patients making the transition from paediatrics covers the way clinics are run and, particularly, how they may differ from the way things are done in paediatrics.
- ✓ Ensure clinic staff know which patients have recently transferred from paediatrics. Placing an identifier on their notes and/or having a member of clinic staff with particular responsibility for these patients helps this process.
- ✓ Make sure clinic procedures and test results are carefully explained at every appointment.
- ✓ Give the young adult the choice as to whether or not their parents accompany them to appointment

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

"I went with my mum a couple of times to get used to it."





staying on an adult ward

What did young adults tell us?

Some young adults were unprepared for differences between paediatric and adult wards.

Wards not attached to specialist units were particularly difficult environments.

“Being on a general adult ward is so alien compared to a paediatric ward”

No one recalled that preparing for the transition to adult health care included explanations about the differences between a paediatric and adult ward.

“It didn’t real get explained and it was a bit daunting actually because it was an adult ward. I think they just sort of expect you to sort of, just sort of deal with it, I guess.”

Key issues faced by young adults included:

- The health and/or mental state of patients was sometimes upsetting or frightening.

“There were some very ill people and it was quite scary, and if they’re older people are likely to die. So it can be quite a depressing place.”

“The first time he was admitted he was on a ward where it said on the door: ‘Please be mindful of old people roaming’. We were scared and he was scared.” (Parent)

- Being cut off from their usual support networks due to no, or limited, internet access.

“Everything’s online now...so to stay in contact with people you need the internet.”

- A lack of support and camaraderie with other patients; this often contrasted sharply with their experiences on the children’s ward.

“All people want to do on an adult ward, I’ve noticed, is just kind of lay there and feel sorry for themselves.”

- Parents not being allowed to stay beyond visiting hours.

"I didn't like it at first... just kinda left to get on with things on your own, I weren't really used to that... like not having my parents there. So I didn't really like it."

- Ward staff and doctors not recognising that they wanted parents involved in discussions and decision-making.

"It's the doctors on the ward come and see you, and they ask you all these questions, and I just say to em: 'Can you wait til my mum comes back?' Even though I'm 19, I'm an adult... I still find it hard with some questions."

- Ward staff not recognising young adults can often need help or assistance with self-care.

"I went into town for a couple of hours and came back to find the patient in the bed opposite was toileting him because no nursing staff came near" (Parent)

- Finally, boredom was particularly an issue during prolonged stays.

"There's not much you can do on an adult ward apart from sit on your bed, watch telly and drink tea. But there's only so much tea you can stomach!"

"... there's only so much play-station you can play until it does your head in!"

Making a difference

Health care teams

- ✓ Check that transition planning work done in paediatrics covers being an inpatient on an adult ward.
- ✓ Make sure that young adults and their families are informed about admissions to adult wards, including explaining the differences between paediatric and adult wards.
- ✓ Provide information/training sessions to staff on wards which receive your young adult patients about: young adulthood, the condition and any disability/care needs. For some teams/units, this will include working with wards in district hospitals.
- ✓ Where appropriate, make sure patients have an emergency care plan (see section 5).

On the ward

- ✓ Ask the young adult about how they want their parents to be involved in information exchange and decision-making.
- ✓ Consider having flexible policies on extended visits for parents.
- ✓ Remember, young adults might not like to ask for help. Check with parents about care needs too.
- ✓ Young adults with physical disabilities may not be able to use a buzzer, what other systems for requesting help can be offered?
- ✓ Investigate options for washing and resting facilities for parents available in the hospital.



helping young adults deal with uncertainty

Having and making plans, and not just those which concern end of life, helps young adults and their families to live with the uncertainty of a life-limiting illness

“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.”

Having plans in place minimises anxiety and enables young adults, and the rest of the family, to ‘get on with their lives’.

“It’s always nice to know that if something does go wrong, there’s going to be plans to help you.”

What sort of plans do young adults value?

Young adults and their families valued having plans for the following eventualities:

What to do when experiencing worrying symptoms or general ill-health

Young adults and their parents found it difficult to assess worrying health symptoms and act accordingly. Having a clear plan or ‘protocol’ from the clinic about what they should do in such situations, and when to contact the clinic, was said to be enormously reassuring.

“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.”

How future deteriorations will be treated or managed

Young adults wanted to feel confident that their doctor would know when they needed to start planning for future deteriorations. That in itself was sufficient for some young adults to 'park' the issue and not worry about it.

"They don't normally talk about lung transplants until your lung function really gets lower and don't come back up."

The management of an emergency or acute admission

An acute admission can be very traumatic, throwing a spotlight on the fragility of the young adult's life. 'Emergency care plans' covering the young adult's preferences around treatment and parental involvement

in decision-making, as well as their care needs, was reported to make a huge difference.

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

It is particularly important to have an emergency care plan when it's possible that the young adult may be admitted to a district hospital or ward where the clinic team are not based.

"It's good peace of mind for us and also for our son. He knows that if he's taken poorly, the [specialist unit] are immediately going to be notified and they're going to get him straight up there." (Parent)

Things to think about

- ✓ Do the young adults in your care have information and guidance about what to do if they experience particular symptoms or are worried about their general health?
- ✓ Young adults and their parents want to be able to identify when to self-manage and when to contact their GP, the clinic or call emergency services. Straightforward guidance contained on a single side of paper is popular way of presenting this information. Don't forget to include all relevant contact details.
- ✓ Would emergency care plans make a difference to the way acute admissions are managed and how young adults experience them? Remember that

emergency care plans should cover care needs and the young adult's wishes about their parents' involvement in decision-making.

- ✓ Are there other hospitals which may admit your patients? How can you communicate/share emergency care plans with these settings? Do you also need to share plans with ambulance services?

"She gave me a paper, which is like marked in colours... light pink and then it gets darker. So the lightest means a little bit of illness, like a cold, and the darkest is one like an emergency and you should contact 999. And she said, 'You can just contact me'."



conversations around end of life

What young adults and parents told us about planning for end of life

It is not easy to talk about or plan for end of life. Those closest to death were amongst those least willing, or least comfortable, to openly acknowledge the life-shortening nature of their condition.

"I still haven't made any really proper plans 'cos I still don't know what I really want, and when to decide that. 'Cos I still don't know... I'm too young to think about that."

"There may be things that I'd rather not know if they happen 'cos it may be scary... we'd rather not know certain things."

For some young adults talking about or acknowledging death, meant a loss of hope.

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

Having an end of life plan

Very few of the young adults we interviewed had made an end of life plan. However, those that had were relieved to have done so. Parents observed that it enabled ongoing conversations within the family.

"It wasn't nice but... it, it's something that has to be done. And I am glad because it gives you that feeling of... you're prepared. You're never prepared when something like that happens, but at least the wheels will be in 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 so comforting knowing that something like that is in place, which I would say any family should do." (Parent)

In every instance, professionals had been involved in instigating conversations about end of life.



"We made the consultant go and talk to him. He didn't really want to do it, but we didn't feel we could do it. It's just a difficult sort of conversation to have as a parent with your child."
(Parent)

There was a sense that some families were waiting for professionals to raise the issue, and trusted their judgement on when it should be raised.

"If there was a real problem they would be upfront and they would talk to us as parents. If he was deteriorating they would tackle it with us." (Parent)

Supporting parents

Some parents said they needed advice and support from the clinic team to raise issues with their son or daughter.

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

Making a difference

Families told us that the following practice makes all the difference when difficult conversations need to happen:

- ✓ Work with a family's pattern of information-sharing and decision-making.
- ✓ Use trusted and familiar practitioners.
- ✓ If they are involved with the patient, work with staff from hospice and/or palliative care teams.
- ✓ Where possible, share difficult information gradually.
- ✓ Avoid decision-making in crisis situations.
- ✓ Have conversations in familiar environments, chosen by the family.
- ✓ Make a record of decisions and the family's understanding of issues which still need to be discussed or planned for.
- ✓ Make a record of the young adult's wishes regarding their parents' involvement in future decision-making.



developing partnerships with palliative care

"I don't like to have an individual potentially nearing end of life that doesn't have a hospice or community nursing team involved."

The benefits of working with palliative care services

- The support and care available to the young adult and family is broadened and extended.

"The staff at that hospice are a classic example of a brilliant support for us... and once you know the patient has them involved, you know you can relax because we work together well."

- It can enable or support advance care/end of life planning.

"Staff from the hospice may come with the patient to the clinic and we'll talk about it together... We've also had families that have found it incredibly difficult to engage with crisis or end of life talks and we've gone out from the clinic and met in the lounge of the hospice."

- There is a mutual sharing of skills and expertise between the clinic and palliative care teams.
- It can enable young adults to die in the place they want to.

"Most of them are very homely individuals that want to be with their families at home (so) they really love the outreach side of the hospice team, the support that the nursing staff and the carers can give to the family in the home environment."

- The bereavement support needs of parents are more likely to be met.

Perceived barriers to working with palliative care services



- Specialist teams/clinics may not know about local palliative care providers/options, including hospices.
- Specialist teams/clinics may be reluctant to work in partnership with, or lack confidence in, local palliative care services.
- Young adults with non-malignant conditions are viewed as outside the remit of adult palliative care services.

Tips on developing partnerships with palliative care services

- ✓ Find out which palliative care services are available locally.
- ✓ Be prepared to go out and meet teams and visit facilities.
- ✓ Be prepared to offer training and support - recognising that your team will also develop new skills and knowledge through working with palliative care practitioners and teams.
- ✓ **Finally**, recognise that families may be very anxious or resistant to receiving support from a palliative care service. They may need you to support them using these services.

"If you mention the word 'hospice' to families there is a lot of fear because people associate hospice with end of life. So I talk about the skills they can offer... the complex case management, the pain management... breaking it down that way. And I actually go and do joint visits with someone from the hospice team to introduce them and then build the relationship."



when a young adult dies

"...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 untimely. We know from other research that, whatever age their child dies, parental bereavement is different to other forms of bereavement and has long-term consequences for their health and well-being.

"I think nobody likes to think about young people dying, and particularly that sixteen to twenty-four age group... it's obviously very difficult and very different to older people."

Adult health practitioners may not recognise, or feel unable to meet parent bereavement support needs. We found that lack of time, a perceived lack of skills and a lack of knowledge about sources of support are all reasons why practitioners can hold back from providing bereavement support

"I think certainly more could be done... following the death of their child. I've always had major concerns over this... but I don't think we'll be extending any further into this area, 'cos I am not quite sure it's probably our place to do that."

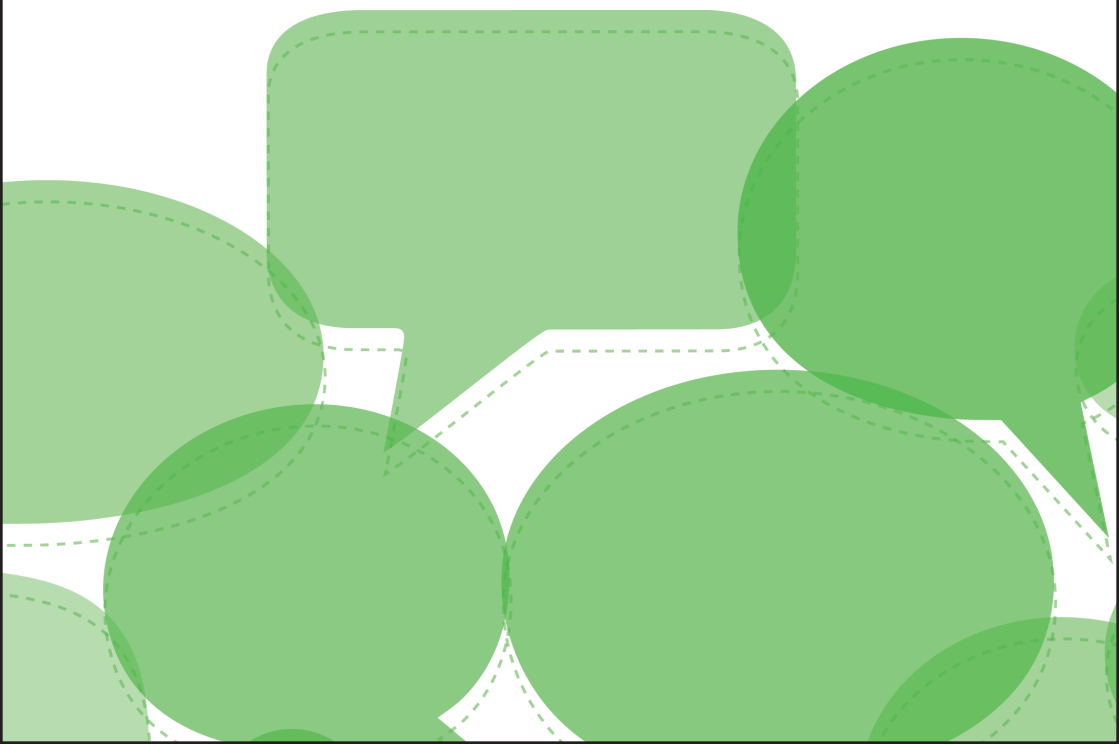
Plus, clinics that did not have good links with local palliative care teams or hospices were often unaware of bereavement support options available within their hospital, other services, the local community or even national support organisations.

"I think bereavement support is something that's better managed when the hospice teams are involved 'cos a lot of them have a post-bereavement service."



Making a difference

- ✓ Find out what sort of bereavement support is provided by your trust and local palliative care service/hospices.
- ✓ Find out if relevant national condition charities offer any bereavement support resources.
- ✓ Investigate national bereavement support organisations: what sort of materials/resources could they provide?
- ✓ Speak to practitioners in these services about the support they could offer and whether they could provide staff training.
- ✓ Discuss whether your team needs to have a protocol about how to respond to the death of a young adult. This might cover: sending of condolence letters; whether to offer a 'de-briefing' appointment; attending funerals; referring on/signposting bereavement support; whether any ongoing contact is offered.





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The STEPP Project

A three year research study funded by the Big Lottery Fund Research Programme initiated by a partnership between Together for Short Lives, Help the Hospices and The National Council for Palliative Care, working with an academic partner at the Social Policy Research Unit at the University of York. The research team at the University of York is led by Professor Bryony Beresford.

