



seven million reasons to care



The Triangle of Care for Young Carers and Young Adult Carers

A Guide for Mental Health Professionals





The Triangle of Care for Young Carers and Young Adult Carers

A Guide for Mental Health Professionals



Acknowledgements

The Triangle of Care for Young Carers and Young Adult Carers: A guide for Mental Health Professionals could not have happened without the involvement of many individuals, especially those from the following organisations: Northamptonshire Carers, Brighton Carers, Chilypep, Sheffield Young Carers, Early Help Team London Borough of Waltham Forest Young Carers Group, South West London and St George's NHS Trust, including the young and young adult carers, parents and staff who answered our questions.

The production of this additional guidance could not have happened without the generous funding from NHS England.

We acknowledge the thought and effort which has gone into creating the best practice examples and are grateful for the generosity of carer champions in responding to the requests to make them widely available.

Your involvement in the development of this guidance has been invaluable.

Authors

Ali Mitchell, Triangle of Care Policy Officer, Carers Trust

Ruth Hannan, Policy & Development Manager (Mental Health), Carers Trust

Published by
Carers Trust
32–36 Loman Street
London SE1 0EH
Tel: 0844 800 4361
Fax: 0844 800 4362
Email: info@carers.org

Carers.org
babble.carers.org
matter.carers.org



www.facebook.com/CarersTrust



www.twitter.com/CarersTrust



www.youtube.com/user/CarersTrust

Carers Trust is a registered charity in England and Wales (1145181) and in Scotland (SC042870). Registered as a company limited by guarantee in England and Wales No. 7697170. Registered office: 32–36 Loman Street, London SE1 0EH.

© Carers Trust 2015

NHS England Publications Gateway Reference 04065

Contents

Introduction and rationale	2
Reflections on the six standards	4
Standard 1 – Carers and their essential role are identified at first contact or as soon as possible afterwards	5
Standard 2 – Staff are carer aware and trained in carer engagement strategies	6
Standard 3 – Policy and practice protocols re: confidentiality and sharing information, are in place	8
Standard 4 – Defined post(s) responsible for carers are in place	10
Standard 5 – A carer introduction to the service and staff is available, with a relevant range of information across the care pathway	12
Standard 6 – A range of carer support is available	13
Useful resources	16



Introduction and rationale

In July 2010, the Triangle of Care, Carers Included: A Guide to Best Practice in Acute Mental Health Care was launched. It has since been updated in 2013¹.

The Triangle of Care approach was initially developed by carers seeking to improve carer engagement in acute inpatient services. It has been successful in effecting positive change for carers by encouraging joined up working between the carer, service user and professionals. It has now been extended to cover all services within a mental health service whether they be an inpatient, community or specialist service. Carers frequently report that their involvement in care is not adequately recognised and their expert knowledge of the ‘well person’ is not taken into account.

You can find out more about the Triangle of Care and the latest guidance at <https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health>.

Since the inception of the Triangle of Care it has been recognised that there is a key gap within its application – supporting young and young adult carers. It has long been acknowledged that young and young adult carers are under recognised and under identified within mental health services, and as a result are often under supported. There are several identifiable reasons as to why this occurs including: lack of their physical presence within adult mental health services, services users reticence in stating they have a child or young person involved in their care,

mental health professionals’ concerns about how to support young and young adult carers and a lack of time and resources available, to name but a few.

In order to gain a better understanding of the needs of young and young adult carers caring for someone with a mental health problem, we carried out consultations with young and young adult carers, young carer workers, mental health professionals and service users across England. It became apparent that there were some common themes – namely that young and young adult carers are under recognised and under supported throughout their caring journey. It is the culmination of the views of all these groups that provided us with the wealth of lived experience that was needed to inform this resource.

As a result of these consultations, Carers Trust has developed the Triangle of Care for Young and Young Adult Carers as a supplementary guide to sit alongside the Triangle of Care. We have highlighted where considered adjustments are required to the approach of the Triangle of Care and its six standards in order to meet the specific needs of young and young adult carers. We have also included reasoning as to why and some solutions to the challenges.

1 Carers Trust (2013) *The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England Second Edition* (Carers Trust).

About Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners, through our unique online services and through the provision of grants to help carers get the extra help they need to live their own lives. With locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is of a world where the role and contribution of **unpaid** carers is recognised and they have access to the trusted quality support and services they need to live their own lives.



Reflections on the six standards

About this resource

This resource has been written as a source of supplementary information to sit alongside the Triangle of Care, Carers Included, for you to use as a reference tool. The intention is for you to use it for self-reflection to help you to ask yourself the question: 'Is our service young and young adult carer friendly?'

Young and young adult carers can sometimes be viewed only in the capacity of risk and safeguarding concerns, however many young and young adult carers are not at an increased risk just because they may live with someone with a mental illness. Services are encouraged to use their skilled staff to sensitively assess risks and act accordingly. We acknowledge that engaging with and supporting young and young adult carers will present some challenges, however if approached without due care, services may well alienate both young and young adult carers and service users alike.

- A young carer is someone under 18 who helps look after someone in their family, or a friend, who is ill, disabled or misuses drugs or alcohol. Older young carers are often described as young adult carers so there is often cross over in terminology.
- Young adult carers are young people aged 16–25 who care, **unpaid**, for a family or friend with an illness or disability, mental health condition or an addiction.

The consultation that informed the resource

Between March 2015 and August 2015 we gathered feedback from young and young adult carers, young carer support workers, mental health service users and mental health professionals. This included:

- Consulting with 137 people across England.
- Carrying out a survey with 95 people.
- Holding eight focus groups with 42 people.

We have collated this feedback and mapped it to the six Triangle of Care standards. Each section of this resource offers some relevant examples of lived experiences of young and young adult carers, which link to the different standards. In addition, we have sourced some best practice examples that also relate to the individual standards and have included a Spotlight on Procedures section to help you look at your own practices and action changes.

Although the terminology and legislation referred to in this guide applies to England the standards and rationale are applicable across the whole of the UK.

Standard 1 – Carers and their essential role are identified at first contact or as soon as possible afterwards

“It felt strange being called a carer. I am supposed to be looking after him, but when I read things about carers I thought that all fits me”.

Young adult carer

Just like adult carers, many young and young adult carers have never considered that they might be a carer – they are just helping their mum, dad, sister, brother, partner or grandparent. Even if/when it is acknowledged that they are in a caring role they may never want to use the term carer. However, identification of someone as a young or young adult carer can be helpful in a number of ways:

- The important role they play in the life of the person they are caring for can be acknowledged.
- They may have vital information to share regarding the care of that person.
- It can allow you to consider the impact of decision making on the young or young adult carer, for example when discharge planning.
- It can help identify their own personal needs as a young or young adult carer, for example the need for a break from caring.
- It can link them in to appropriate and timely support.

“I just think that we just need to be included a bit more. Not in terms of them breaking confidentiality, because I’d never want anyone to do that to me, but when I give them information I expect them to take that information and do something with it, not just to write it down somewhere and forget about it.”

Young adult carer

One of the issues that has been identified in mental health services is that young and young adult carers may not be visible. They may rarely or never attend services with the person they care for. This however does not mean that they do not have a significant caring role in that person’s life.

“Health professionals need to recognise that they do not need to see a child to identify a young carer. Where an adult has parental responsibility they [the health professional] need to investigate the impact on the child and be proactive in seeking appropriate support.”

Young carer worker

The lack of visibility of young and young adult carers who are supporting someone with mental health problems can lead to long delays in identification, which in turn can lead to lack of timely and appropriate support for the child or young adult.

Of those young carers we surveyed, over 90% waited over a year to be identified as a young or young adult carer.

During the consultations it became apparent that young and young adult carer identification was a key issue, with a number waiting in excess of five years to be identified. In the time that elapsed between them becoming a carer and identification, the young and young adult carers often felt very alone and overly responsible for the person they were caring for. They often also had a lack of appropriate information and were not receiving any support to meet their own needs. Consequently, for some, their own mental health was affected, social networks were limited and education or school attendance suffered as a result.



“We’re carers, so you might as well say that we are frontline staff and we could provide them with the maximum amount of information that would help them with their care plans.”

Young adult carer

Young and young adult carers can be experts by experience. Just because someone is young does not mean that they lack knowledge or experience. They may be the person best placed to tell you how the person with mental health problems is behaving, both when they are unwell and when they are well.

By and large, the young and young adult carers that we consulted with and the young carer workers stated that mental health professionals do not communicate with young and young adult carers. This was a key aspect and everyone felt that better communication would improve the experience of young and young adult carers caring for someone with a mental health problem.

“As a rule, contact has been exceptionally limited. Young carers often say that they are not spoken to by mental health professionals and we get very few referrals or exchanges of information.”

Young carer worker

Good practice example:

- The Princess Royal Trust for Carers and Mental Health Foundation (2010), *My Care* (The Princess Royal Trust for Carers and Mental Health Foundation). A report on the challenges facing young carers of parents with severe mental illness. See www.carers.org/sites/default/files/mycare_report_final.pdf

Spotlight on procedures:

- Always ask about children in the household and any help they provide in supporting service users – don’t assume that there are no young or young adult carers involved because you haven’t seen them.
- Be sensitive about using the word carer – many may not identify with this word or find it off-putting when referring to a child/young adult.
- Don’t assume children in the family are *not* in a caring role because there is another responsible adult in the household.
- Build flexibility into your team’s appointment procedure to enable young and young adult carers (who may be in school or college/university) to attend appointments or to have an opportunity to speak to a professional.

Standard 2 – Staff are carer aware and trained in carer engagement strategies

“He shops, he cleans the house, he says to me: ‘Mum, do you not think you need a shower?’ he does the washing, he will walk the dog, he will make sure the dog is fed ... He will take on the household. He will take on me. So he did everything and got himself to school. He said at one point he felt like he was on suicide watch. He’s seen and done stuff that children shouldn’t see and do. He is amazing.”

Mental health service user

There is a common misconception that young and young adult carers only do practical caring, such as household chores or lifting and handling. For young and young adult carers caring for someone with mental health problems, that may be part of the picture but a large part of their role is often about offering significant emotional support. Young and young adult carers may be acutely aware of changes in the behaviour of the person they care for, making them well placed to alert services to a possible deterioration in health, for example.

“I think they should just recognise that whatever age you are, even if you’re like 12 or 13, you are still a carer. They need to listen to carers no matter what age they are. They need to be open and honest and actually listen more than anything.”

Young carer

Young and young adult carers need to be acknowledged and understood. The overwhelming majority of young and young adult carers in our consultations stated that they had not been acknowledged by mental health services and professionals. Yet they often have a wealth of hidden insight and information into the mental wellbeing and illness of the people they care for.

“In terms of my mum’s care, they haven’t communicated with me at all. I’ve been left in the shadows. I think if they did communicate with me they would find it a bit easier to deal with my mum ... but they haven’t.”

Young adult carer

“You know, I don’t think we look at them from the point of view of carers. I think that’s our (mental health professionals’) fault. I’m not saying they’re not carers. I just think that’s my experience.”

Mental health professional

Even when young and young adult carers are visible they are not always recognised as carers. This may be because there is another adult in the household, so it is perceived that the adult must be the sole carer within the home, or because the young person is seen as ‘just’ the sibling or partner, and therefore not a permanent fixture.

“Because we’re not married or anything, he’s ‘just’ my boyfriend, I wonder whether some of them think how much can we really involve this person? Who is she really? How much does she know? ... It’s difficult for young people, they have the view that maybe I’m just transitory, but that might just be my perception, perhaps I just feel in that situation because I’m not involved.”

Young adult carer

Many of the young carers and young adult carers we consulted with were frustrated that they had not been able to share what they know with professionals and would appreciate the opportunity to do so.

“The Care Coordinator never ever tried to contact me. I was calling her over and over again, and when I finally got through to her she just said if he doesn’t bother to contact me then I can’t keep chasing him, I’ve got other patients. Which I understand, the service is busy, but she didn’t make any effort to contact me.”

Young adult carer

The Triangle of Care recommends carer awareness training to help staff understand and engage with carers. It is important that this training has an element on young and young adult carers. See the Useful resources section in this guide. We also recommend you use some of the good practice examples below. Using one of the linked videos as a quick slot in a team meeting might be just enough to get staff thinking ‘young and young adult carer’.



Good practice examples:

- Action for Young Carers Education and Support has produced a video about the experiences of young carers who are caring for someone with mental health or substance misuse problems. See www.youtube.com/watch?v=dXK2bku1MXE
- Avon and Wiltshire Mental Health Partnership NHS Trust has produced a DVD – Working with Young Carers, a Guide for Health and Social Care Professionals.
- The Social Care Institute for Excellence (SCIE) (2009), *Think Child, Think Parent, Think Family: A Guide to Parental Mental Health and Child Welfare SCIE Accredited Guide 30* (SCIE). See www.scie.org.uk/publications/guides/guide30/index.asp

Spotlight on procedures:

- Young and young adult carers provide a great deal of emotional support to service users. Ensure that staff are aware of this impact and that young and young adult carers are consistently referred to support services to help maintain their own wellbeing.
- Young and young adult carers can often know more about a situation than professionals realise. Consider talking to them openly about what is going on. It may alleviate their fears.
- Include young and young adult carers as a regular topic in staff meetings – this is a great way to keep staff young and young adult carer aware.
- Use some of the resources available to help upskill staff in team meetings.

Standard 3 – Policy and practice protocols re: confidentiality and sharing information, are in place

“It’s common courtesy (meeting and discussing with carer), especially when you’re dealing with something as fragile and complex as mental health – it’s not as ‘caring’ as I think it needs to be, it’s very medical model, there’s no person centred approach about it.”

Young adult carer

Sometimes concerns around confidentiality can be a barrier between staff and carers. This can be more polarised for young and young adult carers who have the added barrier of their age and the lack of being physically present in services. Young and young adult carers are often much more aware of what is happening with the mental health of the person they are caring for than is often realised by those involved.

“It makes it worse (not telling/involving you), it makes your imagination run wild. I’ve got a really big imagination. If I wasn’t told something then it would make me think the worst.”

Young carer

Involving and informing young and young adult carers wherever possible can be effective in reducing the stress of their caring role, and the isolation this often brings. If you don’t include young and young adult carers and make use of the wealth of information they may have to offer, you may not be able to develop an effective care plan or risk assessment, for example.

“It would have been nice to have someone to explain it to us, without us having to trawl around – I ended up reading quite a lot of scary stuff.”

Young adult carer

Many young and young adult carers that we consulted with use the internet to find out information about the mental health problem of the person they care for. For some, this has led to them reading age-inappropriate material and misinformation and has increased their anxiety.

“It’s that difficult thing because as a mother you want to protect them so you don’t want them to know but then you get everybody saying to you, especially if they’re old enough, they do want to understand they’re just too scared to ask the questions of you. Would it be sensible, if just for a half an hour, a psychologist sat down and said with them what do you know about how your mum or your dad is and what their illness is and what it means?”

Mental health service user

Young and young adult carers may be concerned about upsetting the person they care for by asking them questions directly about their mental health problems. Service users may at times not wish for any information to be shared with the young and young adult carer. However, listening to them, providing them with general information and referring them to support will not breach your confidentiality policy – it may however have an enormously positive impact on them and their situation. In changes to the Mental Health Act Code of Practice, guidance now emphasises the need for patients to be encouraged and supported to involve carers and that professionals should fully consider

their views when making decisions. More information about this can be found in the best practice section below.

“I’ve taken time, especially during the school holidays, to specifically meet with the children, the parents have agreed to, and also gone in and spoken to the young adult carers and just said, let’s just talk about how you’re doing. What’s your life like at the moment? It takes time which is so precious with our caseloads, but there’s opportunities to do so.”

Mental health professional

It became apparent during our consultation with young and young adult carers that a large number of them are helping the person they are caring for to manage their medication. This may be by prompting them that it’s time to take medication or helping to order or sort the medication. In some instances, it can be around monitoring the effects of medication and having an awareness of when things might not be going according to plan.

“I only realised that he was on the wrong one, because I don’t normally check, I just assume it’s the right one that they give him, and he’s supposed to be on 600 but he was put on 300 which was like a massive gap between it. Before he got medication, ’cos of the voices in his head, he used to rock and he didn’t do that while he was on the medication. So, I realised straightaway, that’s not right, he shouldn’t be rocking again and he shouldn’t be having panic attacks all the time, and then he was shouting to himself which he doesn’t normally do because the voices were getting louder.”

Young carer



Good practice examples:

- South West London and St George's Mental Health NHS Trust has developed a toolkit about parenting and mental health. See www.swlstg-tr.nhs.uk/_uploads/documents/advice-and-support/final-parenting-and-mental-health-toolkit.pdf
- Gloucestershire Young Carers (2006), *Minds, Myths and Me, Fact Pack: For Young People who Live with Someone with a Mental Illness* (Gloucestershire Young Carers). See www.glosyoungcarers.org.uk/wp-content/uploads/2013/01/Minds-Myths-and-Me.pdf
- Carers Trust (2015), *Mental Health Act Code of Practice 1983 – Revised Code of Practice Briefing* (Carers Trust). See www.carers.org/sites/default/files/mha_code_of_practice_briefing_2015.pdf
- Carers Trust (2015), *A Carers Guide to Managing Medicines* (Carers Trust). This booklet includes information for young carers. It is available from some Carers Trust Network Partners in England.

Spotlight on procedures:

- Take the time to actively listen to a young or young adult carer and note their concerns. This will not infringe on your confidentiality policy but it may make all the difference to them.
- Provide age appropriate information about mental health conditions. This could help alleviate anxiety for young and young adult carers and help their understanding.

- Ascertain if a young or young adult carer is involved in helping with medication management and see if there is further support you could offer with this.
- Support your service users to find a way to safely discuss their mental health problems with young and young adult carers who are caring for them.

Standard 4 – Defined post(s) responsible for carers are in place

“You kind of want to feel like you’re building up a rapport with them that they’re actually caring about that person as a person, they’re not just seeing you as the next appointment.”

Young adult carer

Many mental health trusts are now ensuring they have a carer lead on each team. However, for many of these, their focus may be on adult carers. The young and young adult carers that we consulted were all very concerned about the care the person they are caring for is receiving from mental health professionals. Most of them, however had not had any direct contact with mental health professionals. Some may have been in the room with a mental health professional present, but the majority of these stated that they were not spoken to directly or listened to.

“I’ve only been once with my dad because my mum was a bit depressed at the time. Because my dad got put on the wrong medication. He was getting worse instead of better. I had to go with him and say how I was helping him and what was

going on. It was really bad because they weren't actually listening and it seemed like they didn't want to know. I felt like all the pressure was pushed on me."

Young carer

A well informed, young and young adult carer aware carer lead can be more proactive about young and young adult carers' needs and can help to ensure that their colleagues have the knowledge and information they need to effectively support young and young adult carers. A good example of partnership working is a carers centre in London which is working closely with its local mental health trust, providing two part-time dedicated carer leads to work between the carers centre and the trust. They support the trust staff in identifying young and young adult carers and referring them on to appropriate support and have been involved in updating and developing information resources to ensure staff and young and young adult carers are better informed and supported.

"A lot of young people are worried about the stigma and about letting other close friends know about the conditions as they're worried about how they're going to view their parent or the family, and they're also worried about if it's hereditary, are they going to end up with that condition themselves – once it's explained to them that that's very unlikely it does alleviate some stress."

Young carer worker

Having dedicated posts in place, or having young and young adult carers as an identified responsibility for a particular member of staff, can help to ensure that the topic is kept firmly on the table. Other staff can then refer to that staff member if they are uncertain or have any concerns. However, this should not

replace the need for all staff to be young and young adult carer aware and to take individual responsibility for ensuring that the needs of young and young adult carers who are caring for service users on their caseload, are being met and that their concerns are being heard.

"I think a suggestion would be, you know like they do assessments for someone that could have a mental health problem. I think the carer should also go through it. So they're talking about themselves but at the same time they also provide information about the person that they care for, so it's an open session."

Young adult carer

The Triangle of Care states that there should be care plans for service users and carers. A whole family approach can be a very effective way to ensure that the needs of the whole family are being met. This is not just an opportunity to listen to the needs and concerns of the young and young adult carer but a good opportunity to find out more information about the person they are caring for.

Good practice example:

- Action for Young Carers Education and Support funds two posts which sit between it and South West London and St George's Mental Health NHS Trust. These are dedicated young carer posts offering support to staff and young and young adult carers.



Spotlight on procedures:

- Ensure that carer lead role descriptions include knowledge about and awareness raising of young and young adult carers' needs.
- Include information about young and young adult carers' needs in your carer awareness training and ensure all staff receive the training.
- Carry out a carer care plan/assessment for all young and young adult carers identified to ensure their views are heard and needs are being met.

Standard 5 – A carer introduction to the service and staff is available, with a relevant range of information across the care pathway

“A blanket approach doesn't work for everybody, so if medical professionals could think outside the box or meet with people who care first it could help.”

Young carer worker

Services need to have age appropriate information for young and young adult carers to accompany their other information sources. Of the 56 young and young adult carers we consulted, none of them had received any information about the services supporting the people they were caring for. Producing age appropriate materials presents a great opportunity to work in partnership with local carers services and young and young adult carers. This will build strong relationships with local partners and young

and young adult carers, as well as helping staff understand what services are available for young carers.

“They basically ignore me. I've been with her and taken her there and stuff like that, and the doctor she's got is really a really nice person, but I'm sort of like 'the little kid' who takes her there and sits there and waits.”

Young carer

Most of the young and young adult carers we consulted did not feel acknowledged or included in services, even though many of them were very involved at home with caring for the service user. Some of the time this can be because the young or young adult carer is not present in services but even when they did attend appointments with the person they were caring for, many fed back that they were either not spoken to or did not feel listened to.

“Like she'll acknowledge me, she'll be like 'how are you today?' but she won't really engage in conversation. They don't tell me what's going on. I'm like hello I'm here! Like sometimes I feel like I should know stuff”.

Young carer

Services need to be proactive and make time to meet with young and young adult carers to discuss how a service operates, answer questions and provide information that could dispel fear and confusion for young and young adult carers who are caring for someone with mental health problems. This is especially relevant if the person they care for has a period where they are very unwell and has to spend time as an inpatient. As children are often not allowed on inpatient mental health wards, providing opportunities to understand what happens and assuage fears are vital.

Taking the time to explain what is going on and reassuring them that the person they care for is being well looked after can help to alleviate these concerns.

“I’ve also heard people say that when they go to appointments that people will behave totally differently to what they may behave at home ... I think involving carers in those appointments or even a separate meeting would be really helpful so they can get a true picture of what is going on at home. There is a lot of shut down, a lot of dependence and co-dependency that goes on in some of these situations that’s really difficult for young people to manage.”

Young carer worker

There is a lot of frustration for young and young adult carers, as what they experience and live through at home may never be seen or acknowledged by mental health professionals. While professionals may not be able to act upon second hand information from them, just actively listening to and acknowledging a young or young adult carer’s experiences may help them to feel less alone in what may be a very difficult and stressful situation.

Good practice example:

- Salford Carers Centre and Greater Manchester West Mental Health NHS Foundation Trust arranged a ward walk for young carers. When a ward was closed for refurbishment they took the young carers around to help dispel their concerns and put their minds at ease. It was from this experience they then set up a carers group at the hospital for young carers.

Spotlight on procedures:

- Include the requirement for staff to actively engage with young and young adult carers, in your written procedures.
- Develop some age appropriate information for young and young adult carers – a great opportunity to work in partnership with them.
- Involve young and young adult carers in discussions about care planning – invite them to meetings, if appropriate.

Standard 6 – A range of carer support is available

“Well, the fact was I didn’t really (know about support available for young carers). It was the school that referred her. She wasn’t getting out and about and mixing as well and trying to do the bits and pieces, and she’s still got homework to do and things like that. They are looking for a way to try and give her something enjoyable really, for her.”

Mental health service user

There are lots of great and innovative young and young adult carer services out there but they are not always reaching hidden carers. These support services could be the one thing that helps keeps a young person afloat during difficult times. The young and young adult carers, service users and mental health professionals that we consulted all had very positive things to say about the young and young adult carer services they are in contact with and these services are highly valued by all who use them.



“Having support – people to talk to, and having a break and feeling like you don’t have to stress. Having a couple of hours to yourself with other people just talking about stuff that’s not at home.”

Young adult carer

“Not having to worry about everything that’s going on at home, and being somewhere else away from it.”

Young carer

Young and young adult carers services take many different forms, offering things such as assessment and support, groups and activities, social media support, trips out, school support and residential. The common theme expressed was that young and young adult carers need and appreciate time out from their caring role and the opportunity to spend time with other young people who are in similar circumstances to them.

“There’s just a mutual understanding, I can let my hair down and just be myself. You don’t have to worry, you’re just there to have a good time with everybody. It’s like a massive breather, it’s a break and it’s just very good to get your confidence and socialise with people that get it. We’re all here for similar reasons and it’s great when we get to come together.”

Young adult carer

Being a young or young adult carer can be a very isolating experience. Even if they have good friends, they may not feel able to share what is going on at home with them due to the social stigma around mental health or concerns that they won’t be able to understand or relate to their experiences. Young and young adult carers services offer an opportunity to talk about these experiences with other young

and young adult carers or specialist support workers in a safe environment, without any pressure or judgement.

“Having someone to talk to. ’Cos the person you look after you can’t really talk to them and say you’re actually stressing me out. Like I would never be able to say that to my mum, but having someone to talk to who you can approach. It’s just nice to have someone who listens to you. It’s nice that they don’t judge you and that they care.”

Young carer

Young and young adult carers often have to grow up fast and may not get to enjoy being a child or young adult in the same way as their peers. Young and young adult carers services can offer them the time and space to let go of their responsibilities for a short while and have some fun.

“It was nice to have somewhere to act younger, ’cos as a carer you have to grow up rather quickly and do things you wouldn’t do at your age, so it was nice to have somewhere to be a bit more immature than you were at home.”

Young carer

Young carers and young adult carers in England have rights to care and support, either for themselves, or for the person they care for so that they do not have to do so much (or any) caring. A young or young adult carer could be referred by the NHS to their local authority for assessment and possible support.

A young carer’s assessment will determine what the young or young adult carer’s circumstances are, and their need for support. Support can be provided directly to the young or young adult carer to meet these needs, and some support needs can be met by providing services for the person they care for.

Depending on the young or young adult carer's age, and the age of the person they care for, these rights come under the Children and Families Act 2014 or Care Act 2014.

There is a duty on local authorities to ensure that carers receive an assessment on the appearance of need for support. The assessment must consider whether the young or young adult carer is willing, and able, to continue to care. It must also look at whether the young or young adult carer is working, training or in education, or wishes to be so.

Young adult carers under 18 are entitled to a transition assessment under the Care Act. This is to explore what support they may be entitled to after they are 18, and to look at helping them get ready for adulthood. This should help raise their aspirations and support them to achieve the outcomes that matter to them.

Of those we surveyed, over 60% of young and young adult carers had not had a formal carer's assessment or support plan completed.

Good practice examples:

- Greater Manchester West Mental Health NHS Foundation Trust set up a regular meeting in a family room for young carers. The young carers set the agenda and invite speakers to the meetings, for example a pharmacist attending to talk to them about medication.
- Gloucestershire Young Carers in partnership with 2gether NHS Foundation Trust developed the Family Mental Health Empowerment Project. The project ensures that no child or young person takes on the majority of care for an adult once they are discharged from mental health services. See <http://static.carers.org/files/whole-family-support-for-young-carers-affected-by-parental-mental-ill-health-6661.pdf>

- Carers Trust (2015), *Know your Rights: Support for Young Carers and Young Adult Carers in England* (Carers Trust). A useful booklet written for, and with, young and young adult carers with information about getting a social care assessment and support. You can also find more information on www.carers.org/knowyourrights or contact your Carers Trust Network Partner.

Spotlight on procedures:

- Ensure you have up-to-date information about young and young adult carer services in your area and that it is part of your admissions procedure to provide this information to services users and young and young adult carers.
- Ensure staff know where to find this information and are sharing it with young and young adult carers and their families.
- Put this information somewhere which is accessible to young and young adult carers, for example on a carers notice board in a public area.
- Ensure procedures include time to speak to young and young adult carers and provide them with information on support for them in their own right.
- Invite your local carers services to your team meeting to explain what they can do for you and young and young adult carers.
- Always offer to refer to your local authority for a carer's assessment, even if the NHS Trust undertakes its own assessment.



Useful resources

Young adult carer services in your area

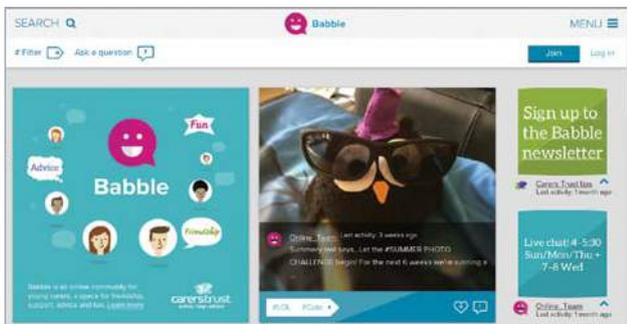
Carers Trust Network Partners support young adult carers in many parts of the UK. This includes offering:

- Practical and emotional support such as breaks and counselling.
- Clubs, activities and holidays.

To find a local Carers Trust service, call **0844 800 4361** or visit **Carers.org**.

If you can't find a carers service in your local area then you can search for a young carer service online or get in touch with Carers Trust by emailing **support@carers.org** and we can search for you.

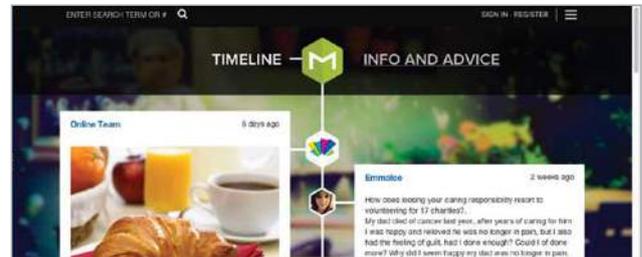
Babble



Visit **babble.carers.org** or email **youngcarers@carers.org**

Babble is Carers Trust's online community where young carers under 18 can find others in a similar position, chat, have fun, share experiences and access information and support online from an expert team.

Matter



Visit **matter.carers.org** or email **matter@carers.org**

Matter is Carers Trust's service for carers aged 16–25. This online service enables young adult carers to post photos, update statuses, ask for help and share their thoughts and comments from wherever they are.

Carers.org



Visit **Carers.org** or email **support@carers.org**

Carers.org is the Carers Trust service for adult carers, with users aged 18 to 80+, with a focus on sharing knowledge and finding solidarity, backed by access to expert and authoritative welfare information.

- Further information on the Triangle of Care can be found at: <https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health>.
- Action for Young Carers Education and Support has produced a video about the experiences of young carers who are caring for someone with mental health or substance misuse problems. See www.youtube.com/watch?v=dXK2bku1MXE
- Avon and Wiltshire Mental Health Partnership NHS Trust has produced a DVD – Working with Young Carers, A Guide for Health and Social Care Professionals.
- Carers Trust (2105), *A Carers Guide to Managing Medicines* (Carers Trust). This booklet includes information for young carers. It is available from some Carers Trust Network Partners in England.
- Carers Trust (2015), *Know your Rights: Support for Young Carers and Young Adult Carers in England* (Carers Trust). A useful booklet written for, and with, young and young adult carers with information about getting a social care assessment and support. You can also find more information on www.carers.org/knowyourrights or contact your Carers Trust Network Partner.
- Carers Trust (2015), *Mental Health Act Code of Practice 1983 – Revised Code of Practice Briefing* (Carers Trust). See www.carers.org/sites/default/files/mha_code_of_practice_briefing_2015.pdf
- Gloucestershire Young Carers (2006), *Minds, Myths and Me, Fact Pack: For Young People who Live with Someone with a Mental Illness* (Gloucestershire Young Carers). See www.glosyoungcarers.org.uk/wp-content/uploads/2013/01/Minds-Myths-and-Me.pdf. Produced in collaboration with young carers.
- Gloucestershire Young Carers in partnership with 2gether NHS Foundation Trust developed the Family Mental Health Empowerment Project. The project ensures that no child or young person takes on the majority of care for an adult once they are discharged from mental health services. See <http://static.carers.org/files/whole-family-support-for-young-carers-affected-by-parental-mental-ill-health-6661.pdf>.
- South West London and St George's Mental Health NHS Trust has developed a toolkit about parenting and mental health. See www.swlstg-tr.nhs.uk/_uploads/documents/advice-and-support/final-parenting-and-mental-health-toolkit.pdf
- The Princess Royal Trust for Carers and Mental Health Foundation (2010), *My Care* (The Princess Royal Trust for Carers and Mental Health Foundation). A report on the challenges facing young carers of parents with severe mental illness. See www.carers.org/sites/default/files/mycare_report_final.pdf
- The Social Care Institute for Excellence (SCIE) (2009), *Think Child, Think Parent, Think Family: A Guide to Parental Mental Health and Child Welfare* SCIE Accredited Guide 30 (SCIE). See www.scie.org.uk/publications/guides/guide30/index.asp





Carers Trust
32–36 Loman Street
London SE1 0EH
Tel: 0844 800 4361
Fax: 0844 800 4362
Email: info@carers.org

Carers.org
babble.carers.org
matter.carers.org

 www.facebook.com/CarersTrust

 www.twitter.com/CarersTrust

 www.youtube.com/user/CarersTrust

Carers Trust is a registered charity in England and Wales (1145181) and in Scotland (SC042870).
Registered as a company limited by guarantee in England and Wales No. 7697170.
Registered office: 32–36 Loman Street, London SE1 0EH.

© Carers Trust 2015