

# Supporting young carers and their families

Information for health care  
professionals





# The Children's Society

The Children's Society works through local and national partnerships to change children's lives for the better.

The Children's Society is an expert service provider that delivers outcomes to meet your priorities for families, children and young people in your area.

Close partnership working with our funders, added together with our local knowledge and expertise means we provide innovative solutions, which deliver outcomes that maximise the impact of your available funding.

We are passionate about our work. We work with you in a transparent and flexible way. We are fully committed to meeting agreed outcomes every time.

We have worked alongside service commissioners in local authorities and the wider public sector for over 125 years. We currently provide services to over 60 local authorities across the UK.

We have experience in a comprehensive range of services that are tailored to meet individual needs. Our work spans from prevention through to intensive targeted support services.

The Children's Society's Include Programme offers information, training and support to both statutory and voluntary sectors who work with young carers and their families. More information and a range of information materials and resources including a Good Practice Guide for Practitioners are available at [www.youngcarer.com](http://www.youngcarer.com) or call 01962 711511.

To find out about our full range of services that will achieve your outcomes, provide value for money and deliver local solutions contact us on 0845 612 9402 or visit [www.childrenssociety.org.uk/services](http://www.childrenssociety.org.uk/services)



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# Who are young carers?

*“The term young carer should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances... a young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well being or educational achievement and life chances.”*

ADASS and ADCS (2009) *Working Together to Support Young Carers - A Model Local Memorandum of Understanding between Statutory Directors for Children's Services and Adult Social Services.*

While most children and young people help parents to some degree some may be taking on caring responsibilities that are inappropriate for a child and that have a negative impact on their own well being.

The 2001 census found 175,000 young carers in the UK. Many of these will have significant unmet needs.

***The key to change is the development of a whole family approach to needs led assessments, to ensure that service provision is child focused and family orientated.***

(Key principle 2<sup>6</sup>)

One of the priorities of *Recognised, valued and supported: next steps for the Carers Strategy* is that children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive.



# What are the issues for health professionals?

The carers strategy recognises that GPs, community health professionals and hospital staff have a vital role to play in young carers lives. Health professionals are likely to be the first people that a family turns to for help with an illness or disability. Whether you work in the hospital or community, with adults or children you may be the only person who is able to ask the right questions to find out that a child is taking on caring responsibilities. Timely intervention could prevent a child undertaking inappropriate levels of care.

The General Medical Council recognises that doctors should be aware of the needs and welfare of children and young people when they see patients who are parents or who are cared for by children or young people.<sup>2</sup>

School nurses have a responsibility to be aware of and offer support to children and young people who are affected by illness in the family or bereavement.<sup>3</sup>

*"We need a doctor to talk to about personal stuff."*

(Young carer)

*"I quite often go in with my mother when she goes to the doctor, but they still don't recognise the fact that I'm a young carer and still don't pay attention or give time to that matter."*

(Young carer)





## What tasks might young carers be carrying out?

Some examples of the tasks young people undertake are:

- **Household chores** – including washing, cooking and cleaning on behalf of the whole family.
- **Personal/nursing care** – such as giving medication, changing dressings, assisting with mobility.
- **Intimate care** – washing, dressing and assisting with toilet requirements.
- **Emotional support** – monitoring and meeting the emotional needs of the person.

- **Childcare** – helping to care for younger siblings, including escorting to school, in addition to other caring tasks.
- **Other** – household administration such as paying bills. Accompanying the cared-for person to hospital. Acting as a translator for non-speaking sensory impaired, or those whose first language is not English.<sup>4</sup>

Recent evidence has shown that many young carers are responsible for administering medication to parents who have serious mental health problems. This has serious implications for the safety of both the young carer and the parent.<sup>5</sup>





There are many reasons why young people take on levels of care that are inappropriate for their age. It may be because of:

- The structure of the family itself and the level of care needs.
- The nature of the illness or disability including speed of onset, its acceptability or whether it is an episodic illness.
- A lack of effective services from outside the family, if the person does not meet eligibility criteria or the services are inflexible.

Some families may not know about the services or support available to them. Some families may be reluctant to acknowledge children's caring roles or involve agencies in their family situation as they fear family break-up. It is also important to recognise that there may be differences of view between children and their parents about appropriate levels of care.

*"My Mum won't accept support as she thinks she is OK, but it is me that ends up with it all."*

(Young carer)

# What impact does this have on a young carer's life?

Inappropriate levels of caring impact on a child's own emotional and physical health as well as their educational achievement and life chances.

The following are examples of the effects on children and young people of providing care:

- Injury caused by lifting or dressing someone.
- Becoming ill themselves as there is no one around to take on the caring and give them a break.
- Developing behavioural difficulties due to emotional problems.
- Missing school or problems with completing homework and getting qualifications.
- Isolation from other children of the same age and from other family members.

- Feeling that they are different from other children and are unable to be part of the group. Some young carers experience being bullied.
- Lack of time for play, sport or leisure activities.
- Problems moving into adulthood, especially with finding work, their own home and establishing relationships.

Some young carers experience being stigmatised or bullied. Some may have behavioural difficulties.

*"It's not just the caring that affects you.... What really gets you is the worry of it all. Having a parent who is ill and seeing them in such a state."*

(Former young carer)





# How do young carers feel about themselves?

Some children see themselves as young carers while others do not. Not all children in families where a member has a disability or illness are young carers. There can also be positives for young carers who are well supported. For example, their caring role can equip them with valuable life skills and give them special relationships within the family. It is important to differentiate between a normal level of caring and an inappropriate level. It is also vital to listen to the child's perceptions and to understand the issues and factors that may have led them to becoming a young carer.

*"We wouldn't want to give up caring because we love them too much. If we gave up caring we would have to change our whole way of life, but we would like help and people to take notice of us."*

(Young carer)

*"I would like them [agencies] to learn more from talking to our family."*

(Young carer)





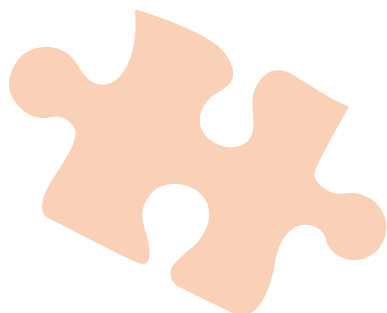
## How can you identify situations where support for young carers and their families might be needed?

A young person may be involved in the care of an adult or child who consults you about:

- a physical disability or sensory impairment
- a learning disability
- a long term illness
- HIV/AIDS
- mental ill health
- drug/alcohol-dependency

More information about the extent of the impact of the person's condition on the family may be gained by asking the following questions:

1. Who helps to care for the person at home?
2. What effect does their condition and personal care needs have on the family?
3. Is there a child/young person in the family who helps to provide care?
4. How does this affect the child/young person physically, emotionally or educationally?
5. Is there any direct help that would support the young carer?
6. Does the parent need support in their parenting role?
7. What can be offered to help the whole family?





# How can you offer support once you have identified a need?

*Young carers and their families are the experts on their own lives and as such must be fully informed and involved in the development and delivery of support services.*

(Key Principle 3<sup>6</sup>)

When assessing the support required by a young carer it is important to take into account the needs of the whole family and how these needs impact on one another. The *Whole Family Pathway*<sup>7</sup> is a web based resource signposting practitioners to support for young carers and their families. There is a need to be sensitive to cultural perceptions and needs around disability, illness and caring whilst recognising a child's fundamental rights to a safe and secure childhood.

*“No care package should depend on the inappropriate caring role of a child.”*

(Carers (Equal Opportunities) Act 2004 Practice Guidance)

The following may be useful:

- Offering an assessment to the young carer following the Common Assessment Framework (CAF) guidance. Find out more at [www.cwdcouncil.org.uk/caf](http://www.cwdcouncil.org.uk/caf) 9
- Referring the family member who has care needs for an assessment under the NHS and Community Care Act 1990. All young carers are entitled to a Carers Assessment under the 1995 Carer's (Recognition and Services) Act, when the person they are looking after is being assessed under NHS and Community Care Act 1990, S47.
- Carers aged over 16 are also entitled to a Carers Assessment from Children's Services under the 2000 Carers and Disabled Children Act.
- In line with fair access to care services (FACS) guidance, ensure that disabled people are supported in their parenting role. Key elements of the Personalised Adult Social Care System, are agreed and shared outcomes which should ensure

people, irrespective of illness or disability, are supported to sustain a family unit which avoids children being required to take on inappropriate caring roles. (Putting People First, 2007) Direct payments can be used for this purpose. Contact your local Adult Services Department.

If the young person's health or development is impaired or the young person is suffering or may suffer significant harm they should be identified as a child in need and referred to Children's Services for an assessment using the 1989 Children Act using the Framework for Assessment of Children in Need and their Families.

## Registering young carers

The National Health Service Priorities Guidance (Department of Health, 1999d) states that GP surgeries must have registers for identifying carers, including young carers. Bibby and Becker<sup>8</sup> (2000) suggest health agencies keep an up-to-date family tree in health records to assist with identification of who provides care in the family.

## Providing information

Many young carers have explained that although they may undertake much of the caring, they are given minimal information about the health issues or disability. Encourage your client to explain their health condition to their children or to allow you to do so. Find an accessible and appropriate way. Many support groups produce age appropriate leaflets or web pages.

Some of the questions that trouble young people include:

- Can I catch it? Will it happen to me too?
- What caused it? Why us? Is it my fault?
- Can I do anything to make it better?
- Will the person I look after get worse or die?
- What should I do in an emergency?



## Parental mental illness

National Service Framework for Mental Health 1999 standard 6 – Caring for carers outlines the roles and responsibilities of Social Services, GPs, Primary Care teams and others with regards to assessing and meeting carers' needs. See *Supporting children who have a parent with a mental illness*, available from the Include Programme.

## Parental substance misuse

It is important to monitor the well-being of any young person you know is living within a family where there is substance misuse, as they may be exposed to circumstances which compromise their safety. For more information refer to *Hidden Harm: Responding to the children of problem drug users*.<sup>9</sup>

"No-one ever sat down and explained to me and my brother what manic depression was. Mum might have done, but no professional person... if someone had explained what it was it would have helped."

(Young carer)





## Language barriers

It is not good practice to expect young carers to interpret for their families particularly when it involves someone with an illness (Leadbitter H, 2008).<sup>7</sup> It should also not be assumed that limited English is appropriate for situations, which may warrant specific or medical terminology (complex health issues).

### Good practice

- When considering translation services, consult with the family first to find out who would be an appropriate interpreter (gender, nationality), to ensure the needs of the individual are prioritised.
- It is also good practice where possible to use bilingual advocates assisting in understanding the cultural and medical context.
- The use of audio and visual aids may support communication with families in addition to language specific leaflets.
- To find out about local interpreting services in your area contact your local council, or access Language Line for interpreting services: [www.language.co.uk](http://www.language.co.uk)

## Whole Family Pathway

The *Whole Family Pathway* is a free online resource for all practitioners in a position to support young carers and their families; including those from Health, Education, Adults' and Children's Services and the Voluntary sector. This is a useful information sharing and signposting tool and has been designed for practitioners to use alongside *Key Principles of Practice: Supportive practice guidance for those who work directly with, or commission services for, young carers and their families*.

The *Whole Family Pathway* is available at [www.youngcarer.com](http://www.youngcarer.com)

**Whole Family Pathway**

The Children's Society  
Include Programme

**The importance of the whole-family approach**  
Young carers do not care in isolation from the rest of their family. Although they need support for themselves, their needs should also be considered in the context of their whole family.

**A resource for practitioners**  
It is important to ensure that, whoever or however the family (Parent or Child) in need of support first makes contact with an agency, the same process or pathway is followed, and that at all times the outcomes of *Every Child Matters* are considered.  
This is not an assessment tool but a 'map' for both families and agencies to follow so they can see what choices, what responsibilities and what lines of accountability for services may be available.

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## Engage Toolkit

The *Engage Toolkit* is a website for all practitioners supporting black and minority ethnic young carers and family carers – including adults and children’s services, Health, Education and the voluntary sector – and anyone providing services to families affected by ill health and disability.

Funded by the Department of Health, this site brings together information and resources and links to help develop and implement best policy and practice for services to support black and minority ethnic young carers and family carers.

The *Engage Toolkit* is available at: [www.engage toolkit.org.uk](http://www.engage toolkit.org.uk)

## Refugee Toolkit

Funded by the Department of Health, The Children’s Society has developed the *Refugee Toolkit*, an online information and practice resource for all practitioners. Adults and Children’s Services, Health, Education and the Voluntary sector can use it to ensure both asylum seeking and refugee people with children under 18 have access to appropriate health services, and that their children do not have to undertake inappropriate care.

The *Refugee Toolkit* is available at [www.refugeetoolkit.org.uk](http://www.refugeetoolkit.org.uk)



## Young carers projects

Young carers projects have a wealth of expertise about young carers' issues and local needs. Evaluations have shown that the support and activities provided are greatly valued by both the children and their families, for whom they are often the only or main source of support. Projects and direct support services for children help reduce both the sense of isolation experienced by many young carers and their families and the stigma that young carers often feel, particularly when caring for a parent with mental health problems, or problem drug or alcohol use.

There may be a local young carers project or the local school may offer specific support to young carers. Your local Children's Services Department should be able to tell you about this. Or see [www.youngcarer.com](http://www.youngcarer.com)

*"...It's knowing that there is all this group behind you – there when you are feeling a bit low and all you have to do is phone someone up and you know that you have always got people stood behind you, who are caring for you..."*

(Young carer)





# Suggestions from young carers

## attending the Young Carers Festival 2011

1. Use the notice board in the waiting area and provide age appropriate leaflets to promote sources of support for young carers and their families.
2. Ensure that doctors and surgery staff have the training to enable them to identify young carers.
3. Help the young carer (where possible with their parent) to access information about the illness/condition of the person they care for.
4. Ensure that staff are accessible and that young carers know how to contact them. Try to provide continuity of care.
5. When prescribing medication consider whether a young person may be collecting or administering it. Find ways to relieve them of this responsibility.
6. Know where to signpost young carers and their families for support and respite.

*"Young people have a right to know what is happening in their family – we should not have to sit outside doors and listen to find out."*

(Young carer)





## Top ten tips for GP surgeries

1. Raise awareness about young carers amongst all the staff, including receptionists.
2. Consider nominating one member of staff to be a link person who will become informed about the key agencies in your local area offering support to young carers and their families.
3. Add caring role to the electronic patient records of both the young carer and the person they care for.
4. Use the online tool *The Whole Family Pathway* (available from [www.youngcarer.com](http://www.youngcarer.com)) to improve referral of the person with care needs, as well as the young carer, for support.
5. Have a copy of the 'Quick Checklist for supporting young carers and their families' on your intranet (available from [www.youngcarer.com](http://www.youngcarer.com)).
6. Use the notice board in your waiting area to promote sources of support for young carers and their families.
7. When appropriate include children in discussions about their caring responsibilities and consult with them about their family's needs.
8. When prescribing medication consider whether a young carer may be administering it. Find ways to relieve them of this responsibility or if appropriate, offer training.
9. Ensure that GPs are available for young carers to talk to about their situation without them having to wait until they have a health problem.
10. Try to avoid using children as interpreters. Contact your local council, or access Language Line for interpreting services: [www.language.co.uk](http://www.language.co.uk)





## Supporting legislation and guidance

Carers and Disabled Children Act 2000

Carers and personalisation: improving outcomes (DH) 2010

The Carers (Equal Opportunities) Act 2004

Carers (Recognition and Services) Act 1995, S1

Recognised, valued and supported: next steps for the Carers Strategy 2010

Children Act 1989

Children Act 2004

Common Assessment Framework 2010

Direct Payments Guidance 2003  
[www.direct.gov.uk](http://www.direct.gov.uk)

Disabled Persons (Services and Consultation and Representation) Act 1986, S8

Drug Strategy 2010: Reducing Demand, Restricting Supply, Building Recovery: Supporting People to Live a Drug Free Life

Fair Access to Care Practice Guidance (DH 2002)

Framework for Assessment of Children in Need and their Families 2000

Getting it right for children, young people and families. Maximising the contribution of the school nursing team: Vision and call to action (DoH 2012)

Health and Social Care Act 2001 (section 58) amending for Children Act 1989, section 17 re: Direct payments in respect of children

Healthy Child Programme from 5-19 years old (DoH 2009)

Mental Health Act 2007 and 1983

National Service Framework for Mental Health 1999

NHS and Community Care Act 1990

No health without mental health: a cross-Government mental health outcomes strategy for people of all ages - a call to action (DoH 2011)

Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care (DoH 2010)

Putting People First 2007 (HM Gov)

Think Family: Improving the life chances of families at risk 2008 (Cabinet Office Social Exclusion Task Force)

Think Local, Act Personal (DH) 2011

Valuing People: A New Strategy for Learning Disability for the 21st Century

# Resources and further information

## Include Programme

Resources, including an Information pack for GP surgeries which contains the 'Quick Checklist for supporting young carers and their families' and posters.

Access to *The Whole Family Pathway*.

[www.childrenssociety.org.uk/youngcarer](http://www.childrenssociety.org.uk/youngcarer)

## Royal College of Psychiatrists

[www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

Resources for young people who find themselves in a caring role for family members with a mental illness.

## Royal College of General Practitioners

Resources developed together with The Princess Royal Trust for Carers with information from The Children's Society Include Programme.

- Free e-learning programme for health and social care professionals: *Supporting Carers in General Practice*  
[www.e-lfh.org.uk/projects/supportingcarersingeneralpractice](http://www.e-lfh.org.uk/projects/supportingcarersingeneralpractice)
- *Supporting carers: An action guide for General Practitioners and their teams*  
[www.rcgp.org.uk/carers](http://www.rcgp.org.uk/carers)



## Other useful sites

### [www.childrenfirst.nhs.uk](http://www.childrenfirst.nhs.uk)

Age appropriate information on disease and illness.

### [www.youngminds.org.uk](http://www.youngminds.org.uk)

A national charity committed to improving the mental health of all children and young people.  
Tel 020 7336 8445

### [www.sibs.org.uk](http://www.sibs.org.uk)

Information for children growing up with a sibling who has special needs a disability or chronic illness.

### [www.DisabledParentsNetwork.org.uk](http://www.DisabledParentsNetwork.org.uk)

A national organisation for disabled people who are parents.

### [www.nacoa.org.ok](http://www.nacoa.org.ok)

Information for children of alcoholics.

### [www.adfam.org.uk](http://www.adfam.org.uk)

A national organisation working with families affected by drugs and alcohol.

### [www.starsnationalinitiative.org.uk](http://www.starsnationalinitiative.org.uk)

Stars National Initiative, The Children's Society.  
Information for children with family members using drugs.

### [www.youngcarers.net](http://www.youngcarers.net)

The Princess Royal Trust for Carers website for young carers.

### [www.nhs.uk](http://www.nhs.uk)

NHS Choices includes pages for young carers.

*Please note these organisations and resources are listed for your information. The Children's Society does not necessarily endorse them.*





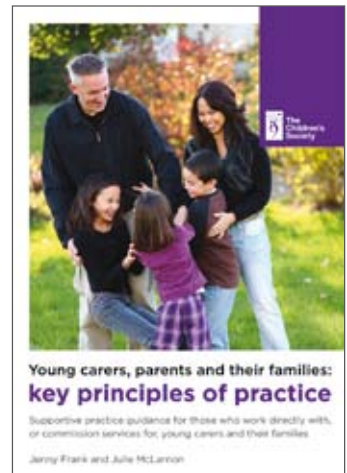
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  - 2 General Medical Council (2007) *0-18 years guidance for all doctors*
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  - 4 Dearden C and Becker S (2004) *Young Carers in the UK: the 2004 report*. Carers UK
  - 5 Aldridge J and Becker S (2003) *Children caring for parents with mental illness. Perspectives of young carers, parents and professionals*. Bristol. The Policy Press
  - 6 Frank J and McLarnon J (2007) *Young carers, parents and their families: key principles of practice*. Young Carers Initiative, The Children's Society
  - 7 Leadbitter H (2007) *Whole Family Pathway: A resource for practitioners*. The Children's Society
  - 8 Bibby A and Becker S (eds.) (2000) *Young Carers in their Own Words*. London: Calouste Gulbenkian Foundation
  - 9 *Hidden Harm: Responding to the needs of problem drug users*. Report of an inquiry by The Advisory Council on the misuse of drugs. June 2003
  - 10 Frank J (2002) *Making it Work. Good practice with young carers and their families*. The Children's Society with The Princess Royal Trust for Carers
- Quotes from young carers in this document are taken from *Making it Work*<sup>10</sup> or are messages from the Young Carers Festival, an annual event organised by The Children's Society and the YMCA, Fairthorne Manor.



# Key Principles of Practice for young carers and their families<sup>6</sup>

- Children's welfare should be promoted and safeguarded by working towards the prevention of any child undertaking inappropriate levels of care and responsibility for any family member.
- The key to change is the development of a whole family approach and for all agencies to work together, including children's and adults' services, to offer co-ordinated assessments and services to the child and the whole family.
- Young carers and their families are the experts on their own lives and as such must be fully informed and involved in the development and delivery of support services.
- Young carers will have the same access to education and career choices as their peers.
- It is essential to continue to raise awareness of young carers and to support and influence change effectively. Work with young carers and their families must be monitored and evaluated regularly.
- Local young carers projects or other targeted services should be available to provide safe, quality support to those children who continue to be affected by any caring role within their family.



Taken from *Young carers, parents and their families: key principles of practice*, available from the Include Programme.

## Include Programme

The Children's Society's Include Programme supports children and young people who care for parents or siblings who suffer from chronic illness or disability. We campaign for change and promote best practice with central and local government and work in partnership with social workers, teachers and health care professionals to deliver solutions that consider the needs of the whole family.

The Children's Society's Include Programme offers information, training and support to both statutory and voluntary sectors who work with young carers and their families. More information and a range of resources, including a Good Practice Guide for Practitioners are available at [www.youngcarer.com](http://www.youngcarer.com)

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