Include Project

Information for health care professionals

The Children’s Society

supporting young carers and their families
Who are young carers?

“Young carers are children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility, which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.”

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.

1. NICKSON, C., HAWKINS, J. Caring & support: issues faced by young carers. ISBN: 0 954 8981 01

2. WRIGHT, R., PEARCE, J. Meeting the complex needs of young carers. ISBN: 1 872 573 61 4
How can you help?

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 National Strategy for Carers (Department of Health, 1999c) states that GPs and other primary care staff, in particular, can provide valuable, sensitive support to young carers and their families.

“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

“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
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.

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 involve agencies in their family situation or be fearful of acknowledging children’s caring roles.
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:

- Problems at school, with completing homework and in getting qualifications.
- Isolation from other children of the same age and from other family members.
- Lack of time for play, sport or leisure activities.
- Conflict between the needs of the person they are helping and their own needs leading to feelings of guilt and resentment.
- Feeling that there is nobody there for them, that professionals do not listen to them and are working only with the adult.
- Lack of recognition praise or respect for their contribution.
- Feeling that they are different from other children and are unable to be part of the group.
- Feeling that no one else understands his or her experience.
- 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.
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
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?
“Young carers and their families are the experts in their own lives and as such must be fully involved in the development and delivery of support services.”

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 (see resources section) is a web based resource signposting practitioners to support for young carers and their families. Following the pathway will help you to understand the assessments and support available for young carers. 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.

The following may be useful:

- Offering an initial assessment to the young carer following the Common Assessment Framework guidance.

- 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.

Parents may value support to enable them to carry out their parenting role. Direct payments can be used for this purpose.

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.

**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.*

**Parental Mental Illness**

National Service Framework for Mental health 1999 standard 6 – Caring for carers outlines the roles and responsibilities of Social Services, GP’s, Primary Care teams and others with regards to assessing and meeting carer’s needs.
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 Carer’s 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

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 (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. School nurses also have a role to play in early identification and intervention (McLure, 8 2001 cited in Frank, 11 2002).

“…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
Refugees and asylum-seekers

It is well documented that many refugees and asylum-seekers arrive in trauma or experiencing mental distress, illness or disability. However, the health problems of asylum-seekers are not always specific to their refugee status and are shared with other deprived or excluded groups. Physical and mental health problems can include diseases linked to poverty and overcrowding, including communicable diseases, psychological and social health problems, stress-related physical health problems. Refugees and asylum-seekers may also have problems with memory, concentration and disorientation, which could hinder learning, including learning a new language. (British Medical Association, 2002)\(^9\)

It is not good practice to expect children to interpret for family members, particularly where there is an illness involved. Families are entitled to interpreting services and multilingual appointment cards available at www.communicate-health.org.uk/card in order to prevent children and young people taking on inappropriate translation roles for a family member who is ill or disabled.

Health services should be integrated, inclusive and responsive to the needs of refugee families. Health professionals and the voluntary and statutory services should have access to information and resources regarding the health needs of BME, Refugee and Asylum Seeking families; such as HARPWEB – www.harpweb.org.uk
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.

“A major worrying task is that most young carers are responsible for giving out medication to the person they care for…. They were worried that one mistake could be fatal.”

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?

“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
Young carers have made the following suggestions on how they could be supported in their role:

- Find a way of enabling your service to identify that a young person is a carer, or that a young carer is involved in the care of the patient.
- Make appointments more flexible.
- Have information about young carers and about potential sources of support visible and accessible for your staff and for patients and carers.
- Raise the awareness of health professionals about young carers.
- Ensure that health professionals liaise with each other.
- Ensure that GP’s are available for young carers to talk to about their situation without them having to wait until they have a health problem.
- Consider adding caring role to details on medical records.

“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
1. Raise awareness about young carers amongst all the staff in your practice area, including reception staff. (Training and resources are available from The Young Carers Initiative)

2. If a patient is discharged from hospital do not assume that there is an adult at home to care for them. Ask the right questions.

3. Use the Whole Family Pathway to improve identification, referral and support of young carers.

4. Consider nominating one member of staff to be a link person who will become informed about the key agencies in your local area that offer support to young carers and their families.

5. Find out if there is a local Young Carers Project or if support is offered in schools.

6. Use the notice board in your waiting area to promote sources of support for young carers and their families. (Pack available from The Young Carers Initiative)

7. When prescribing medication consider whether a young carer may be administering it and, if appropriate, offer training.

8. Have a list of useful websites/leaflets that contain age appropriate information about disability and illness. (See resource section)

9. Ensure that young carers know how to contact a doctor in an emergency.

10. Remember young carers say they wish to be listened to, understood and believed. They also wish to be valued, consulted, respected.

What else can you do?
Supporting legislation

- The Framework for Assessment of Children in Need and their Families 2000
- The Children Act 2004
- NHS and Community Care Act 1990, S47
- Mental Health Act 1983
- National Service Framework for Mental Health 1999
- Fair Access to Care practice Guidance (DH 2002)
- Disabled Persons (Services and Consultation and Representation) Act 1986, S8
- Direct Payments Guidance 2003 www.direct.gov.uk
- Carers (Recognition and Services) Act 1995, S1
- Carers and Disabled Children Act 2000
- The Carers (Equal Opportunities) Act 2004
- Caring about Carers: A National Strategy for Carers (DoH 1999c)
- National Health Service Priorities Guidance (DoH 1999d)

“We need a doctor to talk to about personal stuff.”

Young carer
Young Carers Initiative
The Children’s Society National Young Carers Initiative provides a national focus for people who work to support young carers and their families across England.

The Whole Family Pathway
For more details contact The Young Carer’s Initiative.

www.youngcarer.com
Information for young carers, their families and those who work to support them.

The Princess Royal Trust for Carers
Offers useful information and support for all unpaid carers throughout the UK. It has a website for young carers:
www.youngcarers.net

Other useful websites

www.childrenfirst.nhs.uk
Age appropriate information on disease and illness.

www.youngminds.org.uk
A national charity committed to improving the mental health of all children and young people. Tel 020 73368445
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
A national organisation for disabled people who are parents.

www.nacoa.org.uk
Information for children of alcoholics.

www.adfam.org.uk
A national organisation working with families affected by drugs and alcohol.

www.parentsusingdrugs.org.uk
Information for children with family members using drugs.

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


4 Caring about Carers. DH 1999


9 British Medical Association (2002) Asylum seekers: meeting their healthcare needs. British Medical Association Board of Science and Education


Quotes from young carers in this document are taken from Making it Work (see above) or are messages from the Young Carers Festival, an annual event organised by The Children’s Society and the YMCA.
Key Principles of Practice for Young Carers and their Families

1. There is a need to safeguard children by working towards the prevention of children undertaking inappropriate care of any family member.

2. 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.

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

4. Young carers will have the same access to education and career choices as their peers.

5. 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.

6. Local young carers projects and other direct services should be available to provide safe, quality support to those children who continue to be affected by any caring role within the family.
The Children’s Society

The Children's Society is a leading national charity, driven by the belief that every child deserves a good childhood. We provide vital help and understanding for those forgotten children who face the greatest danger, discrimination or disadvantage in their daily lives; children who are unable to find the support they need anywhere else. Our network of projects helps over 50,000 children and their families each year. Through our pioneering research and influential campaigning, we defend, safeguard and protect the childhood of all children.

The Children’s Society Young Carers Initiative is part of the Include Project.

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The Children’s Society is a registered charity number 221124

With particular thanks to Fareham and Gosport Young Carers for their suggestions for good practice.

This information is available in other formats on request.

Cover photograph posed by model.