



Keeping the family in mind:

a briefing on young carers
whose parents have mental
health problems



Barnardo's

GIVING CHILDREN BACK THEIR FUTURE



'One time the doctor came to see my mum at home. I opened the door to him and tried to tell him that my mum wasn't well. He told me he wanted to speak to an adult in the family. There was only me and my mum and she was ill in bed upstairs. He went to see her and when he came back down, he handed me all her tablets and told me not to let her have any of them.'

Introduction

In the UK today, one in six adults is living with a mental health problem, most commonly anxiety or depression.¹ Many of these adults are also parents whose children are living at home, in fact mental health problems are more common in adults who have dependent children, and lone parents are three times more likely than other parents to experience mental distress.² The emotional wellbeing of parents can have a significant impact on children. In some families, parental distress can lead to children taking on responsibilities that would usually belong to adult family members: they become young carers.

It is difficult to measure the number of young carers whose parents have mental health problems. In 1996, the Office for National Statistics estimated that between 19,000 and 51,000 young carers were living in England, Wales and Scotland, and smaller scale studies suggest that between 6,000 and 17,000 of these children and young people may have been caring for parents with mental health problems.³ Other research

suggests that the real number of young carers may be far higher.⁴ The range of caring tasks undertaken by young carers varies widely, but children who are caring for a distressed parent are more likely to provide emotional as well as practical support than other young carers. A young carer whose parent has a mental health problem may be helping out with a range of everyday chores: cleaning the house, shopping,

cooking or looking after younger brothers and sisters. In addition, some young carers provide significant emotional support and may take responsibility for making sure their parent takes medication or attends appointments with professionals. The level of responsibility a young person takes on can change rapidly as their parent's mental health improves or deteriorates.

1 Department of Health (1999) *National Service Framework for Mental Health: Modern standards and service models*, London, Department of Health.

2 Meltzer H, Gill B, Pettigrew N and Hinds K (1995) *The Prevalence of Psychiatric Morbidity Amongst Adults Living in Private Households, POCS Surveys of Psychiatric Morbidity in Great Britain, Report 1*, London, The Stationary Office.

3 Aldridge J and Becker S (2003) *Children Caring for Parents With Mental Illness: Perspectives of young carers, parents and professionals*, Bristol, Policy Press

4 Cawson et al (2000) *Child Maltreatment in the UK: a study of the prevalence of child abuse and neglect*, London, NSPCC.

The impact of caring

Caring for a distressed parent can have significant consequences when the family is left to cope without any support. Young carers may lack self confidence, find it hard to make friends, or be bullied because of their family circumstances. For young carers whose parent has a mental health problem, these factors are compounded by negative stereotypes of mental distress. A quarter of all young carers report missing school because of their parent's support needs⁵ and over time, young carers are likely to have more restricted life choices than their peers. Young carers whose parents have mental health problems are three times more likely than other children to experience mental health problems themselves.⁶

However, for many children and young people, taking on caring responsibilities can also have a positive effect. Rather than a chore, caring can be part of a loving parent/child relationship, an important and valued contribution to family life. Barnardo's believes

that the families young carers are part of can be positive, nurturing environments, and that parents with mental health support needs can be excellent parents.

5 Dearden C and Becker S (2000) *Growing Up Caring: Vulnerability and Transition to Adulthood – Young carers experience*, Youth Work Press, York

6 Maltser H, Gatward R, Goodman R and Ford T (2000) *The Mental Health of Children and Adolescents in Great Britain*, ONS, London, The Stationary Office.



Our work: keeping the family in mind

Barnardo's purpose is to help the most vulnerable children and young people transform their lives and fulfil their potential. We believe that the best way to support young carers is to work with them as part of a family: keeping the family in mind.

We know that young carers need much more than support for their caring role; they need support for their whole family which goes beyond just the single issue of parental mental distress.

Only 10% of adults with mental health problems are in paid work, so many children whose parents have mental health problems are living in poverty.⁷ Mental distress can place huge strains on relationships and lead to relationship breakdown, which has a long term impact on children. The stigma associated with mental distress can leave both parents and children isolated, terrified of asking for help and fearful that their families will be broken up.

Barnardo's works with hundreds of young carers in our 12 specialist projects across the UK, many of whom care for parents or family members with mental health problems. In 2003-2004, Barnardo's provided support to 1162 young carers and 320 families. We also provide support for parents, including parents with mental health support needs, through our network of 117 parenting and family support projects.

Our specialist young carers' projects provide information, support and advice to children and young people caring for a parent or family member. We run one-to-one sessions and groups where young carers can share their experiences and take comfort

from knowing that they aren't alone. We provide information and advice that can help children and young people understand their parent's mental health problems, and help the family access the support it needs. Some projects also run leisure activities and groups so that young carers can have fun and build friendships.

Many of our projects work with the whole family to make sure that they get the help that they need from other organisations in addition to Barnardo's.

⁷ Stickland H (2003) *Disabled Parents and Employment. Background Paper for the MHT/DWP seminar on 24th November 2003*

CareFree Young Carers' Project

CareFree was established in 1996 to offer a wide range of practical and emotional support to young carers in Leicester and Leicestershire. This includes giving young carers time to be free of caring responsibilities, helping the whole family to get the support they need and providing information to young carers and their families.

CareFree runs and supports 12 young carers groups in the region. As well as providing emotional and practical support these groups offer leisure and social activities to young carers who might not be able to access them otherwise. They also provide an important place for young carers to meet, share experiences and gain support from their peer group.

The project conducts assessments where the needs of the whole family are explored. CareFree

identifies which other services may be helpful and will act as a coordinator for these.

CareFree provides information to young carers and their families and applies for grants to help them with essential household items or to support young people's development. CareFree also advocates on behalf of young carers and their families.

Further details about Barnardo's CareFree service and our other young carers' projects can be found at www.barnardos.org.uk

What we would like to see

- **Adult mental health workers should recognise the role that a young carer plays in their family, and should take time to inform and involve them.**
- **Young carers whose parents have mental health problems should be able to access good quality age appropriate information about mental health problems.**

Barnardo's calls on the UK Governments to give young carers a right to information, through the reform of the Mental Health Act 1983, and the Mental Health (Northern Ireland) Order 1986 and by amending the Mental Health (Care and Treatment) (Scotland) Act 2003.

- **Young carers whose parents have mental health problems should have access to support that values their family, while giving them a space to talk openly and get the help that they need.**

Guidance to adult mental health professionals and other professionals undertaking carers assessments should require that all young carers have their needs assessed, irrespective of whether they are the primary carer. Assessments should have a clear focus on support needs arising from the provision of emotional as well as practical support.

- **Adult mental health services should support parents in their parenting role by providing them with specialist services and by helping them to make contact with their local parenting support projects.**

Barnardo's calls on the UK governments to ensure that assessments for compulsory treatment of parents with mental health problems are undertaken alongside parallel assessments of the support needs of the family as a whole. They should do this by amending the Mental Health Act 1983, the Mental Health (Northern Ireland) Order 1986 and Mental Health (Care and Treatment) (Scotland) Act 2003 so that assessments take place alongside assessments of child and family support needs under the Children Act 1989, the Children (Scotland) Act 1995 and the Children (Northern Ireland) Order 1995.

Guidance on care planning for adult mental health service users, whether in hospital or in the community, should include an explicit requirement to ascertain and meet the parenting support needs of adults accessing mental health services.

- **Adult mental health services should collect information on the numbers of parents accessing their services in order to inform service development.**

All statutory providers of mental health care in the community or in inpatient settings should record the family and parenting responsibilities of adults they provide services to. These statistics should be collated at region and national levels in order to inform commissioning of parenting support and young carers services.





Faiza's story

Faiza is 18 years old. She lives with her younger brother Mahmoud and with their mother who suffers from depression, schizophrenia and diabetes. Faiza looks after her mother. Until September 2004, when he passed away, Faiza also had to look after her father. He was old and suffered from dementia and both he and Faiza's mother needed Faiza's constant support. Neither of them could speak English. The family were reluctant to seek help from social services as they were worried that they would be separated.

Faiza has had to run the household since she was a little girl. She has always paid the bills and arranged the family's finances, did the shopping, cleaning and organised household repairs.

Faiza had to look after the family's health: making sure that her parents took their medication and checking her mother's blood sugar levels. She says, 'I also had to take a parental role over my brother helping him with homework, attending parent's evenings and arranging doctor's appointments.' During the last years of their father's life both children cared for his physical

needs – bathing him and helping him get around the house. 'Doctors were often unhelpful', Faiza says. 'They saw me as a child, whereas I was the primary carer. They didn't respect my opinion.' This was especially the case with mental health services. Faiza consistently asked them to lower her mother's dosage due to side effects but felt that her opinion was ignored.

Her caring duties meant that Faiza was missing school. When she should have been playing at school with friends, she was taking her mother to see the psychiatrist. She says, 'I was

missing out on the social aspect of school – being unable to join friends at the cinema, parties and when they got together.' Faiza's head teacher referred her to Barnardo's when she was 10. Barnardo's has groups in Faiza's area that run in the evenings. There she was introduced to people of a similar age who had similar circumstances and she was given information about mental illness. She was also given an outlet – time away from caring duties where she could enjoy herself and take part in activities that she would otherwise be unable to take part in such as swimming and days out. Staff

would pick her up and return her home afterwards, a service that she says is 'very important'.

Barnardo's gave Faiza help organising visits to her local GP. They helped her with forms and to set-up better ways of managing the family finances. They liaised with social services and arranged for Faiza and her family to attend meetings during evening hours so that they did not conflict with school. Faiza's family had never had anyone to call in an emergency but Barnardo's helped them to access the emergency support of duty social workers.

During Faiza's GCSEs she was really struggling to keep everything together. Barnardo's helped her to put in a request to social services to provide home help for her father. His dementia meant that she worried about his safety whenever she went out. The home help would come twice a day during the week,

helping to take the pressure off Faiza and allowing her to concentrate on her school work.

She says of the work with Barnardo's, 'They make sure that everything is working as effectively as possible – that the family are accessing all of the services that are available. They don't just concentrate on me, but on the whole family.'

Faiza's did well in her GCSE's and achieved 14 qualifications at grades A* to C. This is testament to her commitment and hard work. She is now studying A-levels and is looking forward to going to university somewhere close by so that she can continue to care for her mum. She says 'To put it simply, I wouldn't have been able to achieve this without the support of Barnardo's staff.'

Cain's story

Cain is 15. For most of his life his mum has taken medication to help with her schizophrenia. Cain takes her to the doctors and leaves notes to make sure she takes her medication on time. Some time back his mother was also diagnosed with cancer and was in a lot of pain – Cain and his brother would help her to move around and attend to her needs. Cain does the family shopping, prepares food and takes charge of paying bills and sorting out any problems that arise.

Cain's school work suffered, 'It had been difficult...I couldn't concentrate' he says. As with many children in his position Cain also felt confused about why this was happening. At one stage he even blamed himself, 'I felt like it was my fault.'

When his mum was taken into hospital he went into local authority care. No one explained what was happening to him. He says 'All I got told was 'your mum's not well', they didn't say how long it would be for. They just slammed me and my brother into care.' Cain and his brother were moved around to three or four

different foster care placements most of which were difficult experiences for the boys.

Cain says, 'It made us feel angry. Especially when they said they wanted to separate us, and move us to different areas. We didn't want to live far apart from one another, we always stuck together.'

Since joining a Barnardo's young carers group Cain has become optimistic about the future. He has had someone to talk to who has explained everything about his mum's illness and helped him to understand how the family can cope.

His Barnardo's worker has helped to make sure that the family is getting all the support it should and has called up to make sure that benefits were paid on time. She has visited his school to make sure that the teachers know that Cain has responsibilities outside school that may affect his timekeeping and has involved Cain in a number of activities where he can make new friends. Cain has been on an outward bound holiday and has grown in confidence. He says, 'It's time for you, it's time to do something for yourself.' Cain's family is now on top of things and Cain is sitting his GCSE's.

Sue's story

22 year old Sue works for a Barnardo's young carers project. She became involved after being referred as a young carer herself. Sue started attending when she was 14 as her mum was diagnosed as having serious mental health problems. As well as being a schizophrenic suffering from depression, mood swings and episodes and delusions, Sue's mum also suffered with arthritis and epilepsy.

Growing up with a parent with mental health problems was difficult. When health workers visited the family house they ignored Sue, 'It's as if I was invisible' she says. Sue was given no information about what was going on. Being the eldest of four children she felt especially upset when her brothers and sisters asked her who the man or woman was sitting in the living room talking to their mum and dad, but she couldn't answer them because she didn't know herself.

Sue remembers difficult times at school. 'Mum would come in shouting and swearing in the middle of my lessons and taking us home early. I can remember

when she'd go up to other mums and shout at them for slugging her off behind her back when they weren't. Things got so bad that she accused a supply teacher of hitting my brother and as a result she was sacked. I thought things would get better but they never did. In the end the head teacher had to threaten her by saying he would ban her and us from the school if my mum didn't change her behaviour.'

Sue's mum would get up in the early hours in the morning and become very distressed - turning all the lights on and knocking on people's doors to confront them. Eventually she had to go into hospital. This was a very

hard and traumatic time for the whole family. The environment was frightening and there was little space in which the family could be together comfortably. Sue felt intimidated by the number of new people all around her, saying 'I felt frustrated, confused. I did not know who they were or what they were doing'.

Sue's mum was assigned a social worker and Sue and her brothers and sisters were referred to a local Barnardo's young carers group. With people threatening to contact social services, Sue had been convinced that she would be taken into care. Her young carers worker explained that

this wasn't going to happen.
Sue says 'I cried when she came.
She was the first person to
explain things to us and give us
the opportunity to ask
questions...the young carers
worker came across as
someone who was interested in
what I had to say and someone
who cared.'

Sue now works full time for
Barnardo's and continues to
care for her mum. Through the
efforts of Sue and others, the
psychiatric unit where her mum
had been admitted now has a
Family Room. Children and
young people now have the
choice to visit their parents
away from the ward, which is
more comforting for families.

She says 'The care and support
I've had from Barnardo's, the
feeling that people believe in
me, has been vital in getting me
where I am today.'

Jane's story

Jane, 16, lives with her dad. He suffers from clinical depression, anxiety, stress and an attachment disorder. He finds it very difficult to adapt to new situations, places, or people and becomes distressed easily. What started as feelings once or twice a week escalated into him having the feelings daily and becoming suicidal.

Jane cooks, cleans and generally runs the house. She says, 'There are some days when he lies in bed all day unable to come out...when this happens I try to help him to realise that everything will be OK.'

Jane has cared for her dad since she was 13. The first two years were a very hard and confusing time. 'I felt that I was being kept in the dark', she says, 'and my caring started to affect me quite badly'. Whereas she used to be in the top class, the pressure of her home life began to take its toll and she began to fall behind. Jane didn't want to tell anybody about her home life. 'I felt ashamed', she says, 'and when someone who was supposed to

be my friend told others at school about my dad, I then started to get bullied'. As the bullying became worse Jane started to self-harm. Eventually, at her lowest point, she tried to take her own life. Jane says 'It was a vicious circle...it shouldn't be allowed to get that far'.

After her suicide attempt Jane was assigned a social worker who referred her to a Barnardo's young carers' project. There she has made new friends and has found people who she can trust. 'It's brilliant' she says, 'it might seem like a small thing but it's so important to have a way of getting things off your shoulders'. Barnardo's has helped Jane to understand and

come to terms with her dad's illness and has taken some of the pressure out of her home life by helping her to access all available support. She feels that it has given her confidence and that it represents a 'new beginning'. Jane is now sitting her GCSEs and has been accepted into 6th form college to study for A-levels.



Tanners Lane, Barkingside, Ilford, Essex IG6 1QG Tel 020 8550 8822

Registered Charity No.216250 www.barnardos.org.uk