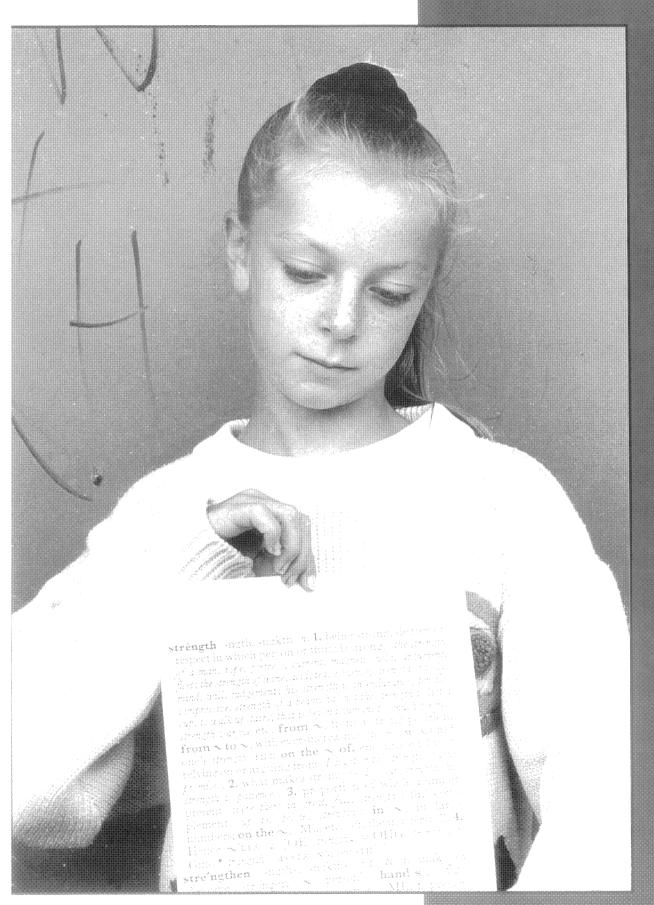
Partners in Caring

A briefing for professionals about young carers



Chris Dearden Saul Becker Jo Aldridge

> Young Carers Research Group

Carers National Association

Crossrads UK

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Partners in Caring

a briefing for professionals about young carers

Effie was called 'little' Effie because she

was quite short for her age. She was ten

years old, but no one who knew her let

that deceive them. She was as strong as

an ox, and just as well, as every day she

had to support the huge body of her

invalid mother and help her from bed to

wheelchair to bathroom to wheelchair,

and finally, at the end of the day, back to

bed again.

Introduction

This Briefing is designed for any professional, from whatever sphere, who may come into contact with young cores and is based on the work

young carers and is based on the work carried out by the Young Carers Research Group (see Aldridge and Becker 1993; 1994). As professionals you may already be in contact with such carers, during the course of your work, without being aware of their existence. We aim to give you the knowledge necessary to help you identify and help such children, and contact names, addresses and telephone numbers of people who are willing and able to offer you further advice and support.

At the back of the Briefing there may be an insert of local contacts and services available to young carers in your area. If not, such information can be obtained from Carers National Association. Their address and telephone number are included at the end of the paper.

From I Want To Be An Angel, Jamila Gavin social, emotion to other childre

Who are young carers?

Young carers are children and young people who provide primary care for a sick or disabled relative in the home. The relative is usually a parent but may, less commonly, be a grandparent or sibling. Young carers perform all the caring tasks associated with adult carers, but those carers under the age of 18 differ since they have the legal status of children. This distinction is important since their status as children contributes to their silence and fear and

to their exclusion from social security benefits and access to services and support.

The exact number of young carers is unknown but estimates based upon surveys conducted in the 1980s (Page,

1988; O'Neill, 1988) suggest that there may be 10,000 children under the age of 18 acting as primary carers (see Meredith, 1991). It is likely that this figure is an underestimation and that the actual number is considerably higher.

Young carers perform a wide range of domestic, personal and intimate tasks. Much of this is hidden - it takes place in the 'private' domain of family life. Many children who perform these tasks do so without any support from paid professionals, and many of these families are living on low incomes. Children who care are denied the

social, emotional and educational opportunities available to other children who do not have to perform these tasks.

The hidden nature of young caring

Young carers are difficult to identify because of their silence. This silence is often the result of fear; fear of coming to the attention of professionals and fear of separation from their families either by the institutionalisation of the care recipient or by the instigation of care proceedings.

Professional groups need to acknowledge these fears and work with rather than against young carers in order to identify and help them. Parents often collude with this silence for the same reasons and also because of guilt and pride and a desire to 'keep it in the family'. Thus professionals may well be in contact with young carers via ser-

WHAT DO YOUNG CARERS DO?

'As well as the physical caring - washing, bathing, dressing, toileting, feeding - and the household tasks of preparing meals, shopping, caring for younger children, managing the household budget, there are constant and overwhelming emotional pressures.' (White, 1989a)

'From the age of nine I was doing all the dinners and everything - I shouldn't have been doing all that.' Debra, age 16

'For a young carer it is not uncommon for the day to start at 5.30am with preparation of breakfast and attendance to the personal needs of the parent. The child may call home at midday to toilet the parent and prepare lunch. In the evening shopping, cooking and cleaning may take priority over school homework. Often a child puts the parent to bed and sleeps in the same room in order to turn him or her during the night.' (Fallon, 1990)

'On a bad day I have to help her get dressed and wash her.' Young carer, age 17

'Well she's got a catheter in so I just have to empty the bag.' Miriam, caring since age 15

'In general [help included] forms of personal care, especially in dressing, and extended to help with feeding, using the toilet, increasing mobility, and lifting the parent.' (Grimshaw, 1991)

'I help her onto the toilet and then sometimes she needs all these pads and that like, so I give them to her and shut the door.' Young carer, age 15

'...I help her to the toilet, shower her, stuff like that.' Sarah, age 15

'To help my dad out I dress him, take him to the toilet, keep him warm, listen for him in the night, give him medicines...' Jas, age 15

vice provision to care recipients, but may be either unaware of their existence or may be ignoring their needs.

It is important to recognise the additional problems experienced by young carers from black and minority ethnic communities, because of a lack of understanding of different racial, cultural and religious

Most young carers are unlikely to

turn for help to formal, professional
organisations. What is possibly more surprising is the lack
of support and help received from the informal sector:
paid professional
rather to paid profession, friends and neighbours.

Networks of support

 ${f I}$ nformal support is sadly lacking, young carers often being neglected by other family members, friends and

neighbours. The 'election' of one particular child into the caring role is common and can even occur where a partner or other adult is present in the household. Informal

help from neighbours and friends will probably only be offered to the care receiver and then only during times of crisis. The needs of the young carers are overlooked.

Formal, professional support also tends to be aimed at care receivers

rather than young carers. Recent research indicates that paid professionals such as social workers, nurses, community care assistants and GPs are failing to recognise and meet the needs of young carers, and failing to engage them in discussion about their caring role. This neglect may well be due to constraints of time and resources and a lack of knowledge about the existence of young carers. However, such a lack of support not only leaves young

I suppose in a way you want to keep it as

quiet as possible. You don't want

anybody else to know about it.

"This information is based on the findings of the research that young carers often need better access to existing services rather than special tailor-made ones.

VOLUNTARY ORGANISATIONS AND YOUNG CARERS

The voluntary sector provides a range of services which young carers could use. However, since most carers are older, the needs and interests of young carers will be very different from those normally catered for by most of the organisations mentioned, and most voluntary organisations, like most statutory service providers, will not have considered appropriate responses. For some it will be difficult to develop targeted support for a small minority of potential users; for others the challenge will be welcome. Carers National Association has pioneered voluntary sector responses more appropriate to young carers, and has helped launch young carers projects in some areas.

Care services such as sitting, shopping etc. are provided by a wide variety of local schemes operated solely through volunteers. Churches and other religious groups are often active in this way, and frequently serve people who are not members of their congregations. More formal home care, prioritising the needs of carers, is provided by schemes such as Crossroads in many areas, using paid, trained care attendants.

Still more formal care is provided by hospices which are skilled in supporting terminally ill people. Some hospices support people in their own homes either as a prelude to or instead of their moving into hospice premises.

Most voluntary sector care services are run in partnership with, and are often funded by, local health and social services authorities. However, most also retain independence in accepting referrals, and have high standards of confidentiality.

Carers support groups and networks exist widely: local contacts can be obtained from Carers National Association. Often they are local and informal - sometimes they are supported by paid workers.

Specialist support projects exist for a variety of needs and conditions including alcohol dependency/misuse, drug dependency/misuse, HIV and AIDS, mental health, learning disabilities, and specific conditions such as Parkinson's Disease, head injuries and many more. These organisations sometimes have respite and substitute care arrangements, sometimes mutual support groups. Nearly always they provide information and frequently confidential counselling. Victim Support schemes cater for people and their families who are victims of crime.

Voluntary counselling services include intensive, face-to-face services and more rapid access telephone services. In addition to locally run and managed services, there are national organisations such as ChildLine and Stepfamily, and local groups of national services such as the Samaritans. Churches and other religious communities also frequently offer counselling and emotional support. More practical help, including advice on money and benefits, is provided by Citizens Advice Bureaux, law centres and other community centres, although most will be more used to dealing with adult enquirers than with children.

Voluntary youth services are widespread, some independent and some run in partnership with the local authority. They typically provide recreation and social contact through clubs and activities. It is not clear how well-resourced they would be to support young carers who find it difficult to get out, but some youth projects have developed to tackle social need and it is worth asking what role local youth groups and services might play.

Voluntary services to families and children include projects run by national agencies such as the NSPCC, National Children's Homes and the Children's Society, in some areas, and local projects such as Homestart schemes also offer home based support in many districts. Childcare organisations and networks including playgroups are widespread.

A summary of this kind cannot cover the spectrum of activity nor give specific directions to local services. In general, more information can be found through local 'umbrella' groups such as Councils for Voluntary Service or (for rural areas) the Rural Community Council. There are also black and other ethnic minority 'umbrella' groups and community centres in most cities and towns with significant ethnic minority populations, which cater for a variety of needs of their respective communities, including the needs of younger people."

Jon North - Co-ordinator, Nottinghamshire Association of Voluntary Organisations

YOUNG CARERS AND THE MEDICAL PROFESSION

"Based on current research, young carers are an invisible group of children both to those responsible for the care of adults, those responsible for paediatric services and to family doctors with responsibility for the family as a whole. The consequences of caring lead to a wide range of disabilities which often will continue long term. These include physical disability as a consequence of injury caused by lifting, emotional disability as a result of the stress upon unsupported young carers and educational disability as a result of missed schooling. In combination, these give rise to a sharp decrease in the quality of life in childhood as well as disadvantages in adult life in terms of mental health and qualifications for employment.

Among the issues that arise for the medical profession is the need to consider the whole family rather than the individual patient. Although this is emphasised in training, this does not always appear to be the case in practice. A service for young carers requires doctors to establish a framework in which information on the health of a family rather than the health of an individual is shared and actively processed. The network that needs to be accessed to provide the best support for the young carer must go beyond health service contacts to include local education and social service departments.

Data on young carers is hard to find. Perhaps there is one in every school or every GP practice. It would be a desirable development that every health record includes an up to date family tree, that individuals with disabilities are identified and the question asked, 'Who is the carer?'. The combination of family tree and services tree will provide a basis for ensuring that young carers and their needs are not overlooked."

Dr Leon Polnay F.R.C.P., D.C.H. Consultant Community Paediatrician; Reader in Child Health

carers very much isolated, but also means that they have a limited amount of information and knowledge regarding the care receiver's condition, treatment and care management.

It seems that professional intervention often occurs only at times of crisis or when the law is broken. Such interven-

tion is likely to heighten fear and further distance young carers from professionals who may be able to help. Children who care are frightened that they may be taken into care or that their loved one will be hospitalised.

The effects of caring

Young carers' lives are often painful and distressing and the effects of caring can be complex. One such effect

is the increased likelihood of poverty in families where children act as carers. This poverty is associated with loss of parental income, particularly in lone parent families where

child caring is more common (see Meredith, 1992), and the increased costs associated with long term illness or disability.

The social security system does not accommodate young carers. Although they perform an adult role as carers, they are still legally children and as such not entitled

to benefits. Those over 16 who are not in full time education may be able to claim depending on their own and the care recipient's circumstances.

A child's psycho-social development may be impaired by caring. Caring restricts many aspects of children's lives, their social opportunities, friendships and education. The responsibilities of caring can place a curfew on children, restricting the time available for friendships, leisure and

hobbies - all important aspects of childhood. These responsibilities may also result in persistent lateness and absenteeism from school. The physical nature of many car-

I don't like social workers. I can cope.

Claire, 16

When they did find out I was looking after him and that he had a brain tumour, social workers didn't really do much about it. Then I was taken to court and threatened to be put into care.

Jimmy, 16

THE EDUCATION SERVICE AND YOUNG CARERS

"Young carers are not always easy to identify in school as young people are often unwilling to talk about their role at home as young carers. This is a very private part of their lives centred around a loved one - a parent, grandparent, sibling or other relative. To discuss this caring role within the home makes a young person feel that he or she is betraying a trust.

Teachers are often in the best position to notice a change in a young person and can set the referral procedures to the Education Welfare Officer in motion. This will result in an assessment visit being made to the home for various reasons: poor attendance, lateness, tiredness in class, deteriorating schoolwork, homework not handed in, social isolation etc. Many young carers attend school regularly and appear to be 'coping', but with more resources at home could attain even higher results to enhance employment prospects or lead to higher education.

School nurses are also in a position to recognise and offer support to young carers and their families.

Once the needs of the young carer have been recognised, the support network can be put into place after consultation with the young person. This will enable him or her to attend school regularly and punctually, and derive the maximum benefit from the educational provision available.

Ongoing support at school will lower the stress often surrounding the curriculum, examinations, homework and relationships. Increased awareness in schools about the role of young carers will also help staff and pupils understand the pressures these young people have and how they can help by offering support and encouragement."

Ann Bryan Principal Education Welfare Officer, Sefton

SOCIAL SECURITY

Benefits available for young carers and those for whom they are caring

Benefits are not available for anyone under the age of 16, but parents of under 16s will be eligible for Child Benefit.

Invalid Care Allowance (ICA)

May be available if:

- the person being cared for is getting Disability Living Allowance at the middle or highest rate for help with personal care: Attendance Allowance or Constant Attendance Allowance (for further information about these benefits, see below):
- the carer is at least 16 but under 65:
- the carer spends at least 35 hours a week looking after the person;
- the carer is studying for less than 21 hours a week;

Other restrictions do apply and this is not always the best benefit to claim, therefore advice should be sought before claiming ICA. For more information and to claim ICA, get DS 700 Invalid Care Allowance Claim Pack from Social Security offices.

Disability Living Allowance (DLA)

DLA is a tax-free benefit for people who need help with personal care, getting around, or both.

It is only available for people under 65.

For more information and to claim DLA get leaflet DS 704 Disability Living Allowance from Post Offices or Social Security offices.

Attendance Allowance

This is a tax-free benefit for people disabled at or after age 65 who need a lot of help because of their illness or disability. For more information and to claim Attendance Allowance get leaflet DS 702 Attendance Allowance from Social Security offices.

Constant Attendance Allowance

This is an extra amount of money paid on top of war pensions and pensions for a disability or illness caused by an accident or disease at work. It is given if the person needs regular personal attendance.

For more information on industrial injuries Constant Attendance Allowance get leaflet NI 6 Industrial Injuries Disablement Benefit from Social Security offices.

Income Support

This is an income-related benefit for those who don't have enough money to live on.

Carers and the person they care for may both be able to get Income Support, depending on their circumstances.

Normally only people over 18 can claim Income Support, but 16 and 17 year old carers may be able to get the benefit.

Income Support is not normally paid to people who work for 16 hours or more per week.

Receipt of Income Support leads to other benefits such as free prescriptions and help with NHS charges, Council Tax Benefit and Housing Benefit where appropriate.

For more information and to claim Income Support get leaflets IS 20 A Guide to Income Support and IS 1 Income Support - see if you're entitled from Social Security offices.

For more general information on caring and benefits, get leaflet FB 31 Caring for Someone? or telephone Freeline Social Security 0800 666 555 for advice on Social Security benefits, or Benefit Enquiry Line 0800 88 22 00 for advice for people with disabilities and carers.

ing tasks, the possibility of disturbed sleep patterns and worry about the cared for, can all contribute to poor concentration and lack of attention. This combination of factors can restrict educational achievement and future career and employment prospects.

It is therefore very important that those professionals working within the education sector, for example teachers, education welfare officers and school nurses and doctors, be aware of the existence of, and problems experienced by young carers. The hidden nature of young caring may

mean that they are not easily visible or identifiable, but gentle questioning by such professionals who are prepared to listen and believe, may result in the identification of young carers.

Not only does caring impinge on normal childhood activities and experiences, it also has an impact on adult opportunities. Some children may be

forced to continue their caring roles into adult life, because there is no-one else available or because they have been socialised into the role and, because of their limited social horizons, have little choice. Others may be freed from the

caring role either by personal choice (often a very difficult and painful choice) or by the death or institutionalisation of the care recipient, but still be restricted in other ways by the caring experience.

Young carers and stigma

any young carers feel stigmatised because they are M'different'; they do not experience the same type of childhood as other children, and their parents are in some

way perceived as being different. However, whilst many of the problems associated with young caring will be common whatever the nature of the illness or disability being cared for, some young carers are likely to be doubly stigmatised. These are the children caring for parents with mental health problems, problems of addiction or

those with HIV or AIDS.

Such problems are much less visible than physical ones such as Multiple Sclerosis or arthritis, and, arguably, much less socially acceptable.

When I was about 13 mum became unbelievably loud and aggressive, she thought she was a prophet and she would

burst into tears in front of my friends. It was extremely embarrassing.

Ex-Young Carer

AN ADULT CARER TALKS ABOUT YOUNG CARERS

"In our community today are children caring for sick or disabled parents or other relatives, often with little or no help from other family members. These children often care from a very young age, robbed of their lives as children because of the necessity to care. They show extreme loyalty and devotion.

Frequently their caring role involves very personal tasks such as toileting, hygiene, bathing and dressing, as well as shopping, cleaning and washing. Often they have to lift the person they care for, and because of such demanding tasks miss going to school and fall behind with their education. In most cases they are too frightened to ask for help in case they get into trouble. Sometimes they fear the parent being taken away from the home, perhaps leading to the break up of the family. This results in a lack of practical help which has a tremendous impact on their emotional state and in turn, on the development of the rest of their lives. They have no social life and do not mix with other children of their own age. Sometimes they are difficult to identify because they cocoon themselves within the family unit.

We live in a society where the development, well being and safety of our children is of paramount importance. Is it fair that we neglect to address the needs of these children who so obviously need our help? Surely we can provide some form of support that would free them to live as children? The very least we owe them is practical and realistic help, support and training and the comfort of knowing that their family unit will not be broken up. These issues must be addressed without delay."

Lorretta Hurst - Carer

People with mental health problems can sometimes be irrational, unpredictable or violent, and their behaviour, if witnessed by others outside the caring environment, may make their children objects of ridicule. Those who abuse or misuse drugs or alcohol may live a lifestyle bordering on the illegal which is likely to be in direct contradiction to the values taught in schools and wider society. Children who care for such parents are likely to feel alienated, unable to reconcile the two sets of values. Equally, children coping with HIV or AIDS in the home may be fright-

ened to discuss this with anyone due to the presence of fear, ignorance and prejudice throughout society.

It is imperative that such children feel able to speak to somebody since the psychological pressure they experience is likely to be severe. The awareness of such potential problems can be incorporated into discussion within schools so that children are taught, for example, the dangers of drugs or alcohol or unsafe sex, without indulging in victim blaming. This may also require a shift in attitudes by professionals who may not have considered the

ROBERT'S STORY

Robert is a young carer who has for many years cared for a parent with severe mental health problems, although at some points in his life he has lived independently of his parent, due to crises, respite care and a strong desire to live a rich and fulfilling life. Robert's life has been dominated by severe mental illness and the damaging effects that this can bring about. In his own words Robert describes one night in his life which illustrates the problems of caring for someone with severe mental health problems.

"I remember a friend calling to see me one evening. This occasion I remember with particular clarity as it was during a period of respite allowed to me when dad had been hospitalised due to acute depression. This gave me the time to be normal. Feeling safe in the knowledge that my dad was being cared for in hospital, I was free to laugh the evening away, until my doorbell rang late in the night. A neighbour of my dad's stood in my porch with a funereal expression. I can only remember the word 'suicide', the rest of those few moments remains a blur.

My legs nearly gave way as I walked to the neighbour's car, and the short drive to my dad's home was stretched by the frozen fear in my stomach and the confusion in my head. On arrival I was surprised at my ability to deal with the chaos, people and the emergency services, but nothing prepared me for the visually disturbing aspects of a wrist-opening suicide attempt. It was my first time and I was scared.

We got my dad into the ambulance and took him to the Accident and Emergency department of the local hospital. I recall shouting, nearly crying at the paramedic; 'Why didn't they tell me?' I was referring, of course, to the hospital who had neglected to contact me after my dad had discharged himself against medical advice, and who has a long history of self-harm and suicidal intent. No-one in the casualty department seemed to have time for me. My dad was taken care of while I waited to sign forms and surrender the relevant information. The hospital staff worked around me as I comforted my dad, even though throughout his mania he was cruel and indifferent towards me.

My body and mind lacked the energy to walk the five miles home, but I comforted myself through the cold exhaustion by audibly telling myself that I would not be beaten by this, even though I was acutely aware that I was alone in this misery.

Cleaning up the blood in my dad's flat and checking everything was secure took an eternity, and I eventually arrived home at 5.30am. My body felt empty but my head was ready to burst. All I can remember after that is cradling myself tightly to sleep, alone on the floor, in the corner of my cold kitchen.

On reflection, I feel saddened and disgusted at the complacent apathy displayed by health care professionals towards young family carers, who act unsupported and with no thanks, within a community which has little tolerance for people and families who suffer from, and live with the sometimes unending trauma of mental illness.

Also it seems ridiculous to me, when you equate the cost of one telephone call to myself (as the young family carer), with the full financial costs to the emergency services, the wide ranging specialist services involved in the recuperation of my dad, and the massive emotional and psychological impact on myself as a young carer."

YOUNG CARERS' RIGHTS

I think she might live another ten years,

by which time I'll be forty. It'll be too late

to have kids then.

Miriam, caring since age 15

"It is difficult to frame a set of guidelines or recommendations that rest comfortably between the contradictions and tensions inherent in being a child and a carer. A starting point, however, is to identify a set of rights that can form the bedrock from which more detailed and specific guidelines, recommendations or approaches can be developed. These rights are tantamount to a statement of principle. We believe that young carers, as children and as carers, have:

- the right to self-determination and choice (to be children, carers or both);
- the right to be recognised and treated separately from the care receiver;
- the right to be heard, listened to and believed;
- the right to privacy and respect;
- the right to play, recreation and leisure;
- · the right to education;
- the right to health and social care services specific to their needs;
- the right to practical help and support, including respite care;
- the right to protection from physical and psychological harm

(including the right to protection from injury caused by lifting etc.);

- the right to be consulted and be fully involved in discussions about decisions which affect their lives and the lives of their families:
- the right to information and advice on matters that concern them and their families (including benefits and services, medical information etc.);
- the right to access to trained individuals and agencies who can deliver information and advice with appropriate expertise, in confidence;
- the right to independent and confidential representation and advocacy, including befriending or 'buddying';
- the right to a full assessment of their needs, strengths and weaknesses, including full recognition of racial, cultural and religious needs:
- the right to appeal and complaints procedures that work;
- the right to stop caring."

From Jo Aldridge and Saul Becker Children Who Care: Inside the World of Young Carers, Loughborough University, 1993

effects of such discussions on those children directly involved.

Child caring involves loss; loss of income, loss of child-hood, loss of opportunities and ultimately, for some, loss

of a loved one and any positive benefits which caring provided. It is crucial that, wherever possible, professionals try and minimise such losses by intervening sympathetically in the lives of young carers, offering help and support and, above all, listening to what young

carers have to say about their own needs. It is only by listening to the perceived needs of young carers themselves, by valuing and respecting their opinions, that these needs will be met.

In addition to the effects of caring already discussed, there are also issues of dignity, embarrassment, humiliation and degradation. These are issues which affect both the carer and the cared for, but the psychological implica-

tions are likely to be far greater where the carer is a child, and the long-term effects are as yet unknown. We must begin to ask what level of responsibilities *children* should have in family life and at what age, if ever, they should take on primary responsibility and

accountability for the care of other family members. The dividing line between what is and what is not acceptable is a thin one and an issue which needs to be addressed.

Acceptable boundaries of care

If we are to accept and respect young people's rights, we need to try and define acceptable boundaries of care. Currently children are performing a variety of caring tasks for other family members. Some of these tasks are of a practical nature such as shopping, cleaning etc., others of a more personal nature such as dressing, bathing, toileting. It appears that children who care are 'socialised' into such roles from an early age and may derive a sense of selfworth from providing such care. However, their feelings of worth and identity may be compromised and confused following professional intervention which is often associated with punishment and control or correction.

Many of the children's rights suggested by Aldridge and Becker (1993) and contained within other documents such as the UN Convention on the Rights of the Child (1989) and the Children Act 1989, are undermined when children are carers. Caring responsibilities often have a sudden onset and can begin at an early age, preventing the gradual extension of responsibilities suggested by the World Health Organisation.

Parental perceptions

Parents of young carers do not perceive young caring in the same way that children do, but view it more as an emotional and affectionate tie rather than in terms of limited choice. Whilst parents often agree that children should not have to care, many actually want them to continue caring, whilst at the same time acknowledging the unacceptability of their children performing certain, more intimate caring tasks. Invariably the desire for their children to care coupled with the acknowledgement of the unacceptability of much care, leads to guilt and fear.

This parental guilt and fear may result in hostility and secretiveness where professionals are concerned, and many problems may be denied. It is imperative that professionals are sympathetic and adopt a non-judgmental approach in order to allay the fears of both parent and child carer.

Parental responsibilities

 ${f P}$ arental responsibilities extend to acknowledging their children's needs as both child and carer. The parental

WHY PROFESSIONALS SHOULD KNOW WHAT WE DO Young carers speak out

Three young people from the Crossroads St. Helens Young Carers Project outline their views:

"I think it is very important that 'professional people' are aware and understand the difficulties that we have, in order that advice, assistance, guidance and support (both emotional and practical) can and must be found so that we can be helped to lead as normal a lifestyle as possible under the difficult circumstances in which we exist.

People tend to forget that, although the disabled or sick relative for whom we are caring is important, the emphasis must be equally shared with the carer. Let them not forget that these 'children' (which is what we are) have not had the benefit of an education geared to looking after the sick and disabled. So it is up to those who have, to come up with the goods."

Andrea

"When a young carer approaches a professional, for example a doctor, the person in question needs to understand how we feel, and not talk down to us or give us pills because we are depressed, but to advise us and treat us as adults. After all, we are doing a very adult job.

Professionals who are closely involved with children, e.g. teachers, have to be able to identify young carers and not presume that because we do not attend school often, or miss homework, that we are just lazy or troublemakers.

Professionals need to be able to advise young carers on important things such as where to go for financial help and what may be available, and, most importantly, listen and understand.

To do these things professionals need to have knowledge of what we do and how this affects us as people, as children. These people have the power to change things for young carers, make our standard of living better. I just hope they realise this and put their positions to good use."

Jean

"It is very important that professionals know what daily tasks we do, in order to know what we are missing out on.

Once professionals know what we are missing out on, they can then begin to think about how they can help us to develop into a 'normal' adult once caring stops. My most common concern is, 'What kind of future have I got to look forward to?'

It is all well and good for people to tell me that education is a great beginning, but if I fit in my school work around my caring role, my education will be sacrificed in order to fulfil that role.

Each young carer has different circumstances which they have to deal with on a day to day basis. It is therefore not possible to build a picture of a typical young carer in order to assist all young carers. Individual assessment of each young carer's needs is therefore important before professionals can help."

Joanne

control exerted over these children may differ from that found in the 'typical' parent-child relationship because of the parent's desire not to lose their child as a carer (Aldridge and Becker, 1994). Thus parents may not always recognise or acknowledge their children's specific needs as carers. Professionals can encourage and assist parents in this recognition and help to resolve difficulties and meet the needs of both carer and cared for.

Professional responsibilities

 $P^{\text{rofessionals therefore have several responsibilities}} \\ \text{towards young carers which include:}$

- identifying child carers;
- acknowledging their contributions;
- listening to them;

LEGISLATION

Children Act 1989

- Emphasises a 'child-centred' approach.
- Requires the delivery of services to 'children in need'.

'It shall be the duty of every local authority (a) to safeguard and promote the welfare of children who are in need; and (b) so far as is consistent with that duty, to promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children's needs.' 17[1]

'A child shall be taken to be in need if (a) he is unlikely to achieve or maintain, or have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority, or (b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services.' 17[10]

The act also empowers local authorities to 'put together a package of services for a family which could include home help, day-care provision for a family member other than the child in need, or a short-term, temporary placement for the child', where the services are provided to promote the child's welfare (Guidance and Regulations to the Children Act, Volume 2, Paragraph 2.6.).

NHS and Community Care Act 1990

- Emphasises consultation and negotiation.
- Encourages cross-agency collaboration.
- Separate assessment of disabled person and carer's needs should be considered.

- believing them;
- offering explanations about medical conditions;
- assessing their needs separately from those of care recipients (this can be achieved by making use of the carers' assessment);

• recognising that their needs can differ from, or conflict with, those of care recipients;

 recognising different cultural, racial and religious needs;

• consulting with them;

• respecting them as 'partners in caring';

integrating them into existing service provision;

developing new services and resources;

providing information;

• including them in future community care plans and children and family service plans;

removing the fear from provision and support;

protecting them as children and carers;

promoting their rights as children and carers;

• enabling their development by offering choices, including the choice to stop caring;

• advocating for a better deal for children who care.

Obviously some professionals will be better at some of these tasks than others. For example, nurses and GPs will be the obvious choice for explaining medical conditions and terminology, whilst teachers may play an important

part in the early identification of young carers. Professionals can and should acknowledge their own strengths and weaknesses and, where appropriate, refer young carers to others who may be better able to offer specific types of help, advice and intervention.

Having identified young carers, current legislation and local policy guidelines can be implemented to try and help them.

How you can help

 P rofessionals, from whatever sphere, need to work separately and together, to help young carers. The first step is an understanding of what young carers are, what they do and the issues raised by their lifestyles and needs.

YOUNG CARERS AND SOCIAL SERVICES DEPARTMENTS

I used to say to my mum, am I going to

school tomorrow and she used to say

we'll see. I never actually went.

Young Carer, age 15

"At present there is no specific legislation or guidance which requires local authorities to produce plans to assess the numbers and needs of young carers or to make provision to meet need, although several Social Services Departments are using the impetus of the Community Care reforms, the Children Act or Children Services Plan to address this. Consequently the pattern of service varies considerably across the country. This position needs to change. In those local authorities who are responding well, like the Royal Borough of Kingston upon Thames, there are several points worth noting:

- 1. A collaborative approach to researching and identifying the needs of young carers is important. In RBK this involved not only Social Services (including both Children and Families and Adult Services) but Education and Housing Departments, local health authorities and voluntary agencies. It is a good idea to form a network of people from the various agencies to spearhead this task. Carers National Association through its Young Carers advisors can be an invaluable help.
- 2. The whole exercise of needs identification has to be handled very sensitively and possibly based outside the Social Services Department to encourage response. In simple terms it is less threatening to approach a voluntary agency than a statutory body despite the best intentions of the latter.
- 3. Be prepared for the possibility that the needs identified may not be what you expect. Young carers may not regard themselves as such, but as carrying out normal family responsibilities. They may be reticent to reveal problems they face for very good reason. In Kingston we found that more young people were caring for drug abusing parents than we had anticipated.
- 4. Existing services, if scrutinised carefully, may show up the existence of numbers of young carers. Those who receive home help services, for example, may reveal that for most of the time they are cared for by a young person. Sometimes it is simply a case that the right questions have to be asked.
- 5. A lot of effort should go into creating an approach that does not frighten off young carers, is friendly and encouraging, and illustrates that asking for help will not make matters worse. Confidentiality and a willingness to listen to and trust the young person are crucial and need to be reflected in all literature and personal contact.
- 6. Although many existing services will prove to be effective in providing practical and emotional help, some additions may be useful. A helpline offering confidentiality and a local press focus can assist, as can specific training on counselling for staff drawn from local agencies. Peer support groups for young carers with expert facilitators can be beneficial, as can a recognition of the importance of advocacy, for example for a young carer to represent their needs to a school or college.
- 7. Creating and maintaining a separate profile on 'young carers' with the helping agencies and the public is particularly useful in that it keeps up the momentum rather than running the risk of short lived awareness raising which may tail off as staff change. A focus on young carers within the school setting can be a useful part of this process.
- 8. Finally, it is important to move away from the label of young carers as simply 'client' or 'victim'. Most young carers are unlikely to see themselves in this light, are often carrying out tasks requiring considerable skill and decision making ability, and should be at the forefront of any problem definition and in devising helping strategies. Where such an approach works positively it can result in opening up new choices for the young carer."

Roy Taylor, Director of Social Services, Royal Borough of Kingston upon Thames Such an understanding can help in the identification of existing and potential young carers.

Rather than adopting a reactive approach to young carresource in a groers, professionals can adopt a proactive approach, actively Professionals trying to identify young carers, establishing what their needs are and attempting to most those peads. The

attempting to meet these needs. The hidden nature of young caring means that only the most extreme cases may come to the notice of professionals. Therefore action on the part of profes-

sionals is necessary to identify and help these children.

Many of the services already available can be adapted to help young carers and knowledge of what is available in your area is essential. Carers National Association holds a list of specific developments for young carers and can offer advice on what may be available locally. These projects aim to help young carers and provide an invaluable resource in a growing number of towns and cities.

Professionals also need to understand the parent/care

receivers' perceptions of receiving care from a child, and responsibilities in relation to that child. Such an understanding can assist in the sympathetic provision of alternative care arrangements, which need not adversely affect the family unit, providing the needs of

all the family are taken into account and all parties included in discussions and decisions.

This briefing is intended to give you a broad outline of the issues surrounding young carers, in order for you to develop your knowledge and add to your expertise.

WHAT PROJECTS CAN OFFER YOUNG CARERS

being my mum. We can't talk and ask her

what we were like when we were young.

Ex-Young Carer, age 21

"Any project which offers help to young carers must listen to their needs, both as individuals and as a group. When I started the Sefton project two years ago I had no idea of either! A lot of time and energy has to be spent on building up trust with young carers, listening to them and seeking ideas and answers. A starting point is recognition of their role and recognition that they all have different needs. Factors such as class, culture, gender, family structure, personality and, most of all age, must be considered. Acknowledging that their situation and needs will change as they develop is, I feel, fundamental, and any service offered must reflect this. The service must also ensure that it is sensitive, non-oppressive to the dependent relative, and, at the same time, must be child centred.

Being identified or recognised as carer can, for some children and families, be alarming, for others it can be empowering.

I have found that some children want practical or emotional support on a one-to-one basis, either short or long term. Others have found great comfort being introduced to another child who is in a similar position, either on an individual or group basis.

Young carers in Sefton are currently offered regular age related activities, fun days and holidays. This gives them a break, a laugh, a chance to be free from their responsibilities.

Our newsletter, which is edited by a young carer, includes snippets about activities, weekends, etc. as well as specific information about services, and we are thinking about including general information about medical conditions. Usually young carers give a personal perspective about their caring role, in an attempt to share their experiences. The newsletter can also be used as a tool for raising awareness of the issue in the community and with professionals. We ensure the newsletter is non-threatening to families and often the parent will help the child write an article. For some young carers the newsletter is the only section of the service they feel they want or need

The fact that the project is based in the voluntary sector and managed by PSS (Personal Service Society, Liverpool) has, I feel, helped make the service effective. Not only is it seen as non-threatening to young carers and their families, but it is not rigidly based on bureaucracy and is therefore able to be responsive and flexible.

The service is based on a partnership between staff (myself and Liz Gray, young carer worker) and registered volunteers, all of whom have been young carers themselves. They have direct experience of the situation and are committed to ensuring that children who are young carers in Sefton receive help and support. What started off as a genuine attempt to involve young carers in the service, has evolved into ex-young carers delivering some of the services themselves. They take the children on day trips, organise regular outings, 'drop-in' nights and weekends away, as well as befriending individuals. My job is to ensure that they are supported and receive the appropriate training.

The befriending scheme involves 'matching' volunteers to individuals. The matching has happened automatically during the activities and day trips. In my discussions with volunteers and young carers, one of them self selects and it is my role to facilitate and formalise the process. We are only at the beginning stages of offering this service, but this element is, to me, exciting and introduces choice to the young carer. Some clearly prefer that the help and support they need be given by a volunteer, and the young carers say it is an added bonus that the volunteers have been young carers themselves. Befriending individuals or family groups is time consuming and challenging for the volunteers, and obviously if this part of the service is to be extended, more volunteers will need to be recruited and trained. We are already nurturing some young people in the Project who are keen to be involved as volunteers. We are also considering recruiting volunteers who have not been young carers themselves.

The project has also become involved in advocacy for young carers. This role has again evolved rather than been planned. Depending on the age of the child, 'advocacy' can be done on behalf of the young carer, involve modelling what the young carer is to say, or just taking him or her to the Social Service office and sitting with them, encouraging and supporting.

Sefton's model of service delivery is only one possible way forward, but the main message for any project or agency which deals with this issue is to ensure that the voices of young carers are listened to, and services meet their needs in a sensitive way.

Two of our volunteers, Brian and Sharon, have produced 'Diary of a Young Carer in Sefton' (see page 11). This diary is not fictitious but is based on the experiences of a 16 year old young carer."

Pam Howard, Project Manager, Sefton Young Carers

CARERS NATIONAL ASSOCIATION

Carers National Association was formed in 1988 by the merger of two charities to become the national voice for all carers in the United Kingdom. The Association aims to:

- encourage carers to recognise their own needs;
- · develop appropriate support for carers;
- · provide information and advice for carers;
- bring the needs of carers to the attention of government and other policy makers.

The Association currently has a membership of over 10,000 and members support each other through a national network of branches and carers' support groups, all of whom receive regular advice and information from the national, area and local offices.

The Young Carers Project, funded by the Department of Health, was set up in 1990 to look at the special needs of children and young people (usually under 18) who are caring. In 1992 this section became a part of the Association's ongoing work.

The National Young Carers Officer co-ordinates research, development and support work nationally. This involves:

- raising awareness of professionals of young carers' issues and their needs;
- encouraging statutory agencies to plan for young carers when implementing the Children Act and Community Care Act;
- keeping policy makers informed of the needs of young carers;
- developing practical support for young carers at a local level;
- helping set up, supporting and advising local multi-disciplinary steering groups, which is an important part of the work.

The National Young Carers Officer also organises conferences and seminars, nationally and locally, for professionals interested in commencing work on young carers' issues and those already supporting young carers. These give workers an opportunity to learn more about the issues and exchange experiences and ideas. Young carers themselves are encouraged to participate in these events, as well as their local steering groups where many are already members. A small number of Young Carers Development Grants are available to help local groups finance initial awareness raising meetings and the setting up of a steering group.

Young carers often attract interest from the press and media. The Association, in close liaison with professionals with a specialist young carers role, aims to maintain and develop good relationships with journalists and producers in order to present a positive image of young carers.

The Association produces literature about young carers' issues for professionals, and has recently published a Young Carer Information Pack, the first national publication aimed at children and young people between the ages of 12 and 18 who have caring responsibilities. The Pack has been produced in consultation with young people, and aims to offer practical advice and information in a clear, easy to understand format. The Packs are free of charge to young carers and carers, and priced at £2.75 each, including p&p, for professionals. A young carers newsletter, aimed at keeping young people in touch with each other, will be published twice a year.

For further information contact:

Sylvia Heal, National Young Carers Officer, Carers National Association, 20-25 Glasshouse Yard, London, EC1A 4JS Telephone: 071-490 8818 Fax: 071-490 8824

CROSSROADS UK

This national voluntary organisation delivers respite care to over twenty-two thousand people in their own homes annually, thus providing vital relief for primary carers throughout the United Kingdom. Recently the organisation has recognised, and become deeply concerned about the growing number of children who are acting as the primary carer to sick or disabled relatives.

The daunting task of reaching out to an additional area of need will not deter Crossroads from seeking out referrals from professionals and other agencies in order to recognise and act upon the plight of young carers.

Relief from the constant caring role must be found so that young people can grasp the variety of experiences open to them and develop as individuals. The loss of social contact within peer groups can result in young people failing to make important childhood friendships. Vital childhood development processes can be impeded if young carers are prevented from receiving a full, purposeful education or from taking advantage of extra-curricular school activities.

Crossroads aims to give young carers the chance to develop normal social relationships, educational opportunities and a stable emotional life. Crossroads is developing appropriate and sensitive answers to the needs of young carers. Services that involve young people and which will deliver real support.

Crossroads is committed to developing these new initiatives across the UK. We aim to deliver real hands-on help to young carers, whilst respecting their desire to show love and support to relatives.

Research by the Young Carers Research Group at Loughborough University continues to play a key role in raising awareness of problems for young carers.

If the needs of young carers are to be adequately addressed, active support and practical help from Crossroads and other caring organisations is essential.

Acknowledgement

The work with young carers being undertaken by Crossroads UK has been made possible by sponsorship from BT.

For further information contact:

Pat Wallace, Chief Executive, Crossroads National Office, 10 Regent Place, Rugby, CV21 2PN

Telephone: 0788 573653 Fax: 0788 565498

YOUNG CARERS RESEARCH GROUP, LOUGHBOROUGH UNIVERSITY

The Young Carers Research Group at Loughborough University was established in 1992 under the directorship of Dr Saul Becker. The research team consist of Jo Aldridge, Chris Dearden and Betty Newton.

The group conducts applied research and policy evaluation concerned with children and young carers' issues, and works in close collaboration with a multi-agency steering committee and national organisations concerned with carers and young carers.

The group has been working on six funded projects. The first two projects, on the experiences of young carers and their parents in Nottinghamshire have now been completed ('Children who Care'; 'My Child, My Carer'). Both of these projects were funded by Nottingham Health Authority Joint Finance. Current projects include a study of the experiences and needs of young carers and their families in Europe; the production of a Resource and Information Pack for young carers; and the establishment of principles and guidelines for young carers' befriending projects. These projects are funded by Nottingham Health Authority Joint Finance and the Gulbenkian Foundation.

In addition to these current projects the Group will shortly be commencing a number of other projects on young carers' issues for the Gulbenkian Foundation, and will be working in collaboration with Crossroads UK to produce training material for professionals in caring services.

For further information contact:

The Young Carers Research Group, Department of Social Sciences, Loughborough University, Loughborough,

Leicestershire, LE11 3TU

Telephone: 0509 223379/223352/223383, Fax: 0509 238277

A DAY IN THE LIFE OF A YOUNG CARER

This is the diary of a young carer who is also a young parent. Each young carer is a unique person - all have different circumstances and situations. This is one young carer's typical day.

- 7.00am Get up. This is an important time of the day for me as it is quite often the only time I get to myself.
- 7.30am Get mum up: toilet, wash, dress. At this time my loyalties are tested; should I see to mum or my baby first?
- 8.15am Prepare breakfast and medication. This is another pressure put on me what if my mum was to refuse her medication? or I were to give the wrong tablets and something was to happen to her? At whose feet would the blame fall?
- 8.45am Help mum to the toilet, feed my baby.
- 9.15am Mum goes to day centre. Time with baby: wash, dress, play. More pressure is put on me, as sometimes mum becomes very selfish and will go out of her way to be difficult, therefore getting attention.
- 10.00am Do family laundry and cleaning. This is a task that has to be done, and done properly, or I face the barrage of questions such as "Are you coping?" or "Can you manage?" from so-called friends and professionals, i.e. friends of the family, home help and social workers.
- 1.00pm Feed baby and dry washing.
- 1.30pm Do shopping and pay bills. This can be a real problem, having to balance the weekly budget, i.e. food, bills, extras.
- 3.00pm Wait for mum to come home. At this time most kids would be getting home from school and planning the rest of their day with their friends. In my case I can't even go to the corner shop unless someone is there to watch mum.
- 3.45pm Prepare a snack for mum. This can be a very frustrating time for both mum and me, especially as mum has had a stroke and can't speak.
- 4.00pm Mum's medication, feed baby. Again, taking responsibility for mum's medication.
- 4.45pm Cook family evening meal. All of a sudden I have to cook whole meals for the family and still give attention to mum.
- 6.00pm Evening meal, time with baby: change and bath. This is the only time of the day I feel a part of a family and not out there on my own.
- 8.00pm Feed baby and put him to bed. Most mothers look forward to baby's bedtime because they have been with the baby all day, but not in my case. I would just like to spend some quality time with my baby.
- 8.30pm Bath mum, help her to bed. Mum is still centre of attention.
- 9.30pm Prepare baby's feeds. Sort out laundry.
- 11.00pm Time to relax. I am still trying to work out how I will get through the next day.
- 12.00am Feed and change baby, go to bed.

Sharon, a young carer and volunteer from Sefton Young Carers Project, written with the help of Brian, also a volunteer

References and suggested further reading (see also Publications from the Young Carers Research Group):

- Bilsborrow, S. (1992), "You grow up fast as well..." Young Carers on Merseyside, Carers National Association, Personal Services Society and Barnardos. This was the first piece of research to contact young carers directly and gives some insight into their lives and experiences.
- Carers National Association, (1993), Strategies and Structures: Working with Young Carers Conference Report.

Report of a one day conference with detailed accounts of the main speeches and themes.

Elliott, A. (1992), Hidden Children: A Study of Ex-Young Carers of Parents with Mental Health Problems in Leeds, Mental Health Development Section, Leeds City Council.

This piece of research looks at the effects of parental mental health problems on children within families. It includes discussion of the experiences of growing up with mental health problems and recommendations for professionals in contact with children in this position.

Fallon, K. (1990), 'An Involuntary Workforce', Community Care, 4 January. An article discussing the emergence of young caring as a social issue, and its possible incidence. In common

with many other articles, this one cites the figure of a potential 10,000 young carers nationwide.

Gavin, J. (1991), I Want to be an Angel, Mammoth.

A collection of children's stories including one about a black young carer.

- Grimshaw, R. (1991), Children of Parents with Parkinson's Disease: A Research Report for the Parkinson's Disease Society, National Children's Bureau.

 This piece of research looks at the effects of a particular disease Parkinson's on children in families, and covers areas such as the medical knowledge children possess, their home life and the effects of their parents' illness upon themselves.
- King's Fund Centre, (1992), Young Carers in Black and Minority Ethnic Communities: Workshop Day Report. This report, based on a day conference at the King's Fund Centre, examines the issues surrounding black and minority ethnic young carers. It is one of the few reports available of this kind.
- Meredith, H. (1991), 'Young Carers', Contact, Summer. This was one of several articles written by Huw Meredith and designed to raise awareness of the issues surrounding young carers.
- Meredith, H. (1992), 'Supporting the Young Carer', Community Outlook, May.

 Another awareness raising article, outlining the issues and the research and policy developments in the area.
- O'Neill, A. (1988), Young Carers: The Tameside Research, Tameside Metropolitan Borough Council. A survey of carers which also included information on young carers.
- Page, R. (1988), Report on the Initial Survey Investigating the Number of Young Carers in Sandwell Secondary Schools, Sandwell Metropolitan Borough Council. An early survey of schoolchildren carers.

Segal, J. and Simkins, J. (1993), My Mum Needs Me: Helping Children with Ill or Disabled Parents, Penguin.

This book examines the experiences of children with sick or disabled parents. Most of the children concerned have a parent with multiple sclerosis and some perform a caring role. Included are many quotes from both parents and children who have undergone counselling.

Tyler, A. (1990), 'Helping the Children to Cope', *Combat Newsletter*, Spring.

An article which gives information on Huntington's Disease and its implications for children. This article is particularly useful since it gives advice on supporting children within a family environment where there is a hereditary, terminal disease and also advice on giving information to children.

- White, P. (1989a), 'The Costs of Caring', Young people Now, May.
- White, P. (1989b), 'Caring for the Caring', Young People Now, June.

 These articles by Peter White also help to give general information about young caring, raise grangeness and

These articles by Peter White also help to give general information about young caring, raise awareness and keep the issues in the public arena.

Wingate, C. (1994), 'Who Cares?', Nursery World, 28 April.

This article provides an overview of the position of Britain's young carers and refers to new initiatives from Crossroads UK and Carers National Association.

Young Carers Link (1992), March.

This is a magazine published by Carers National Association and designed for young carers.

Recent and forthcoming publications from Loughborough University Young Carers Research Group (in date order):

- Aldridge, J. and Becker, S. (1993), Children Who Care: Inside the World of Young Carers, Department of Social Sciences, Loughborough University. This was an original piece of research undertaken in Nottingham which gives a detailed account of the lives and experiences of child carers, often using their own words. Biographies of the children and detailed descriptions of their caring duties are included.
- Becker, S. and Aldridge, J. (1993), 'The Lost Children', Community Care, 18 March p.23.
- Aldridge, J. and Becker, S. (1993), 'Excluding Children Who Care', *Benefits*, issue 7, pp.22-24.
- Aldridge, J. and Becker, S. (1993), 'Inside The World of Young Carers', *Carelink*, 19 p.3.
- Aldridge, J. and Becker, S. (1993), 'Children Who Care', *Childright*, no. 97, pp.13-14.
- Aldridge, J. and Becker, S. (1993), 'Children as Carers', *Archives of Disease in Childhood*, vol. 69, pp.459-462.
- Aldridge, J. and Becker, S. (1993), 'Punishing Children for Caring: The Hidden Cost of Young Carers', *Children and Society*, vol. 7, no. 4, pp.277-288.
- Aldridge, J. and Becker, S. (1994), My Child, My Carer: The Parents' Perspective, Department of Social Sciences, Loughborough University. This is a follow up report to Children who Care and

discusses the issue of child caring from the point of view of the adults being cared for. It is intended as a companion volume to the first report.

Becker, S. and Aldridge, J. (1994), 'The Price of Caring', *Community Care*, 20 January, pp.18-19.

Becker, S. and Aldridge, J. (1994), 'The Rights and Wrongs of Children Who Care', in Franklin, B. (ed.), Children's Rights: A Handbook of Comparative Policy and Practice, Routledge (in press).

Dearden, C. and Becker, S. (Forthcoming), Resource and Information Pack for Young Carers, Loughborough University/Nottingham Health Authority, August 1994.

Aldridge, J. and Becker, S. (Forthcoming), A Case for Befriending: A Report to the Gulbenkian Foundation, Loughborough University, July 1994.

Becker, S. (ed.) (Forthcoming), Children Who Care in Europe: A Report to the Gulbenkian Foundation, Loughborough University, November 1994.

Dearden, C. and Aldridge, J. (Forthcoming), *Multi-Disciplinary Training Pack*, Loughborough University in association with Crossroads UK, November 1994.

Dearden, C., Becker, S. and Aldridge, J. (Forthcoming), 'Children Who Care: A Case for Nursing Intervention?' in *British Journal of Nursing*.

This Briefing was produced by the Young Carers Research Group, Loughborough University, and funded by Carers National Association, Crossroads UK, Nottingham Health Authority Joint Finance and the Calouste Gulbenkian Foundation.

Further copies of this Briefing are available from the Young Carers Research Group at Loughborough University, from Carers National Association and from Crossroads UK. The cost is £2.50 per Briefing (includes p&p). Discounts are available for bulk orders (£2.00 per briefing for 10-50 copies; details on request for discount on larger orders). Please send payment with order (cheques should be made payable to either 'Loughborough University (YCRG)', 'Carers National Association' or 'Crossroads UK', depending on which supplier you use).

Two Publications from the Young Carers Research Group

Children Who Care

- inside the world of young carers -

ISBN 0 907274 01 3 £7.99 per copy (inc. p&p)

and

My Child, My Carer

- the parents' perspective -ISBN 0 907274 04 8 £6.99 per copy (inc. p&p)

To order, please send a note of your requirements with a cheque/postal order made payable to 'Loughborough University (YCRG)' to Betty Newton, Young Carers Research Group, Department of Social Sciences, Loughborough University, LE11 3TU

Tel 0509 263171 extn 4607 (Receipts will be sent with orders)

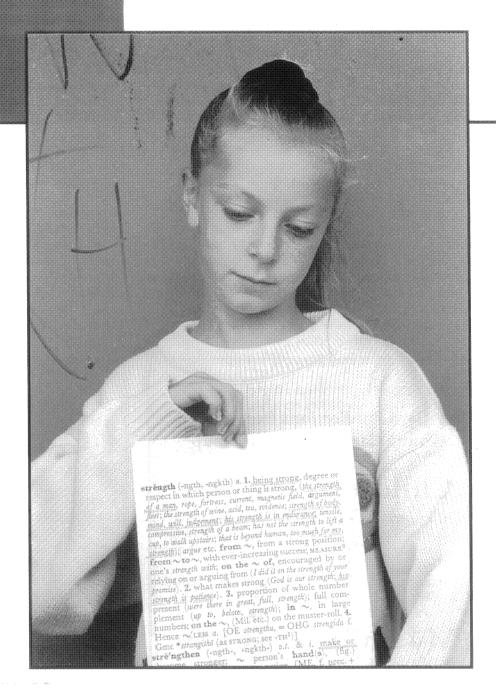
Carers National Association

Young Carer Information Pack

This pack is free to young carers and £2.75 to others (inc. p&p)

To order, please send a note of your requirements with a cheque/postal order made payable to 'Carers National Association' to Janet Wilson, Carers National Association, 20/25 Glasshouse Yard, London EC1A 4JS

Tel 071 490 8818



When a young carer approaches a professional, for example a doctor, the person in question needs to understand how we feel, and not talk down to us or give us pills because we are depressed, but to advise us and treat us as adults. After all, we are doing a very adult job.

Professionals who are closely involved with children, e.g. teachers, have to be able to identify young carers and not presume that because we do not attend school often, or miss homework, that we are just lazy or troublemakers.

Professionals need to be able to advise young carers on important things such as where to go for financial help and what may be available and, most importantly, listen and understand.

To do these things professionals need to have knowledge of what we do and how this affects us as people, as children. These people have the power to change things for young carers, make our standard of living better. I just hope they realise this and put their positions to good use.'

Jean, a young carer from St. Helens