Section 2: About Young Carers

This section provides an overview about young carers. It contains information on what is meant by the term 'young carer', along with the particular issues and challenges that can be faced by this group of children and young people.

In this Section you will find Information Related to:

- Who are Young Carers?
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Who are Young Carers?

Young carers are children and young people who look after someone in their family who has an illness, a disability, or is affected by mental ill-health or substance misuse. Young carers often take on practical and/or emotional caring responsibilities that would normally be expected of an adult.

Although definitions of a young carer can vary, the Scottish Government has defined a young carer as:

'A child or young person aged under 18 who has a significant role in looking after an adult or sibling who is experiencing physical or mental illness or disability or who requires care due to misuse of drugs or alcohol'.

Research shows that 81% of young carers care for a parent, often a single parent, and just over a quarter look after a disabled sibling. It is often the case that young carers who care for a disabled sibling are overlooked. Furthermore, it is important to remember that not all children and young people whose parent or sibling is ill or disabled will be a young carer.

The tasks carried out by young carers vary considerably and depend on factors such as the nature of the illness/disability and the family circumstances. Some young carers may undertake high levels of care, whereas for others it may be frequent low levels of care. Either can impact heavily on a child or young person.

Young carers may be involved in providing support through some or all of the following:

- Practical tasks such as cooking, housework and shopping.
- Physical care, such as lifting, helping a parent on stairs or physiotherapy.
- Personal care, such as dressing, washing and helping with toileting needs.
- Managing the family budget, collecting benefits and prescriptions.
- Administering medication.
- Looking after or 'parenting' younger siblings.
- Emotional support.
- Interpreting, due to a hearing or speech impairment or because English is not the family's first language.

At the end of this section you can find some young carer case studies, which are intended to bring to life the many difficulties faced by this group of children and young people.

What are the Effects of Being a Young Carer?

A young carer's personal and physical development, physical and emotional health, as well as social opportunities can all be affected by the family situation and their caring role.

Young carers learn practical and caring skills at an early age and often take on practical and/or emotional caring responsibilities that would normally be expected of an adult. However, it is important to remember that they are young people with the same emotional needs as others their age.

- Stress, tiredness and mental ill-health are common for young carers.
- Their physical health is often severely affected by; caring through the night, repeatedly lifting a heavy adult, poor diet and lack of sleep.
- Many experience traumatic life changes such as bereavement, family breakdown, loss of income, shifts in housing and seeing the effects of an illness or addiction on a loved one.
- Inappropriate caring roles during childhood can impact later in life, affecting a young carer during the transition to adulthood, or in adulthood itself. This can include the long term impacts on physical or emotional health, further education and/or career opportunities.

Why are Young Carers Hidden?

Many young carers receive no (or very little) help during their childhoods. It is difficult to believe that their issues go unnoticed but there are several reasons for this.

Adult Services often fail to recognise their clients' needs as parents and Children's Services often intervene too late when a young person's caring role has already affected their well-being and in some cases when they are at crisis point.

Adults and Children's Services often struggle to work together effectively and often fail to look at the needs of the whole family.

Families are often wary of intervention by services and conceal illness, particularly mental ill-health and substance misuse, while some parents don't recognise their child's caring role. In addition, young carers may feel they will be bullied if other young people find out about their caring role.

Life Skills and Positive Aspects of Caring

Despite the barriers that are often present for young carers, many young carers also feel that the experience of being a young carer can have many positive aspects. Young carers can be highly self-motivated multi-taskers, coping with and achieving at school while undertaking a caring role. Many transfer their caring experiences into career and job choices having developed the key skills and competencies needed for their families to function. These skills include effective communication and management capabilities, often coupled with a mature outlook. There is, however, currently no way of accrediting these skills so that colleges or employers recognise them.

Compassion, consideration, determination, empathy, understanding and tolerance of illness and disability can also all be acquired but the negative aspects of caring often outweigh the positive.

It is important that recognition of a caring role does not inadvertently encourage the continuation of inappropriate care, nor that caring becomes a cause for celebration and not action. It is also important that careers advisors do not assume that the care profession should be the only career path for young carers and that they help them to explore all options. Equally, young carers' abilities to cope and achieve should not be allowed to mask their need for support.

Young Carers and Education

Young carers, like all young people, have hopes and dreams, stresses and worries. However, not only do they have the pressures experienced by all those their age, they also have the added responsibilities that would normally be expected of an adult.

School can be a haven for a young carer where they can forget their caring responsibilities. For some, school can be a place of safety and normality away from the chaos of home. For others, school can be a miserable place: where they are misunderstood, bullied and where the pressures of school work compound their already difficult lives.

As a result, young carers can often encounter barriers to their learning. The impacts of these can be variable, severe and enduring. Schools should aim to counter such impacts by removing or lowering any additional barriers to their learning caused by family circumstances. It is important to ensure that young carers have the same access to education and career choices as their peers.

It is important to remember that your school doesn't need to do everything and instead should aim to involve a range of professionals, local and national agencies to provide a broad spectrum of support.

Underachievement

There are strong links between being a young carer and underachieving at school, with many failing to attain any Standard Grades at all. Of young carers aged 11-16, 27% are missing school or experiencing educational difficulties and nearly all miss school when the person they care for is having difficulties.

Missing School

Young carers can miss significant amounts of their education due to their family situation and caring role. This may involve missing large chunks of school or frequent shorter absences. It is likely that a significant number of the so called 'serial truants' responsible for much of the non-attendance statistics are unsupported young carers, who have dropped out because they cannot juggle the combined demands of caring and those of education. This can lead to young carers being locked into unpaid caring roles well into adulthood with no hope of independence or a career. Some young carers are physically present in school, yet admit to feeling unable to access their education fully due to worry or stress. Also, they may find accessing extra-curricular activities difficult or impossible due to caring demands, financial reasons or transport difficulties.

Behavioural Issues

Some young carers keep negative feelings to themselves to protect their parents from additional stress and anxiety. However they are not always able to contain these feelings at school. The real reasons for a young carer's behavioural problems might not be discovered until it is too late to make positive changes. Some young carers become very quiet and withdrawn, whereas others react with negative behaviour. Others immerse themselves in their work and are model students.

Missing Deadlines

Young carers sometimes find meeting homework and coursework deadlines difficult because of the additional demands on them at home. They may not cope with the accumulative stress of trying to juggle home and school life.

Bullying

Young carers are often the victims of bullying at school. Some young carers are bullied because of the condition or illness of the person they care for; whilst others can be bullied because they appear to lack social skills or seem more mature than young people of the same age. Social isolation at school will impact on a young carer's well being and their ability to fully engage in school.

Bereavement and Loss

It is important to remember that although young carers (and families) may try hard to juggle their responsibilities, including keeping up with their education, sometimes it is the latter that falls off the list of priorities when up against other issues such as the fear of a bereavement, or bereavement itself.

Legislation and Guidance

There exists a great deal of legislation, policy and guidance concerning young carers which affects schools.

The Education (Additional Support for Learning) (Scotland) Act 2004 and 2009

This legislation introduces a framework for providing for children and young people who require additional support with their learning for any reason. The Act places certain duties on local authorities to identify and monitor the additional needs and the support provided, and to respond to parental requests for an assessment.

Getting it Right for Young Carers, The Young Carers Strategy for Scotland 2010-2015

This is the first national young carer's strategy published by the Scottish Government. It states:

'Young carers may require additional support to help them make the most of their school education and be included fully in their learning. Local authorities have a duty to provide this'.

The strategy outlines a number of action points to be implemented by local authority education services to support young carers in schools. These include:

- By 2012, if they have not already done so, Local Authority Education Services will wish to revisit their policies, procedures and approaches for identifying young carers in schools, to reflect the impact of current policy and legislation, including Curriculum for Excellence and the Supporting Children's Learning Code of Practice.
- By 2012, if they have not already done so, Local Authority Education Services will wish to review the approaches they have in place for ensuring that young carers are supported in school and to ensure that

they are not disadvantaged because of the impact their caring has on their attendance, achievement, attainment and behaviour.

The strategy sets out how its production links with the 4 capacities which form the foundation of the Curriculum for Excellence and Scottish Government's child-centric approach, Getting It Right for Every Child (GIRFEC)

Curriculum for Excellence

Curriculum for Excellence (CfE) provides opportunities and support that is tailored to the needs of the individual learner, so that every child and young person can develop the attributes, knowledge and skills they will need if they are to flourish in life, learning and work and to be effective contributors, successful learners, confident individuals and responsible citizens.

Health and Wellbeing is one of the building blocks of the Curriculum for Excellence. Through this curriculum there will be a more active approach to mental health and emotional wellbeing, which can be of benefit to young carers.

Getting it Right for Every Child (GIRFEC)

GIRFEC is a fundamental way of working across all statutory and third sector services and is the delivery mechanism for improving outcomes for children and young people. It is a partnership approach that puts the child, including those with caring responsibilities at the centre. It identifies and builds on existing family and community supports to promote all children and young people's wellbeing and improve outcomes.

GIRFEC promotes a coordinated and unified approach to identifying concerns, assessing needs, agreeing actions and outcomes, based on the Wellbeing Indicators.

The Children and Young People (Scotland) Act 2014

The Act covers a variety of areas relating to the wellbeing of children and young people and aims to improve the way services support children and families by promoting co-operation between services. It enshrines element of the

GIRFEC approach in law. The Act puts children and young people at the heart of planning and services to ensure their rights are upheld.

To improve the way services work to support children, young people and families the Act will:

- Ensure that all children and young people from birth to 18 years old have access to a Named Person;
- Put in place a single planning process to support these children who require it through the Child's Plan;
- Place a definition of wellbeing in the legislation;
- Place duties on public bodies to co-ordinate the planning, design and delivery of services for children and young people with a focus on improving wellbeing outcomes and report collectively on how they are improving those outcomes.

United Nations Convention on the Rights of the Child (UNCRC)

The UN Convention on the Rights of the Child (UNCRC) is a key strand underpinning activity to improve outcomes for all Scotland's children and young people, including young carers. It is important that all agencies that have an impact on the lives of young carers promote and protect their rights, taking into account:

Article 2 – All rights apply to all children without discrimination and children should be protected from discrimination.

Article 3 – In all actions concerning children, the best interests of the child shall be a primary consideration.

Article 6 – Every child has the right to life, survival and development.

Article 12 – Every child who is capable of forming their own views has the right to express those views freely.

Article 15 – Every child has the right to meet with other children and to join groups and organizations, as long as this does not stop other people from enjoying their rights.

Article 28 – Every child has the right to an education. Primary education must be free. Secondary education must be available to every child.

Article 31 – Every child has the right to relax, play and take part in a wide range of cultural and artistic activities.

Young Carer Case Studies

The charity Carers Trust has produced a number of case studies highlighting the real life experiences of young carers. These case studies are written by the young carers themselves and with the permission of the Carers Trust, we have adapted them for inclusion in this resource.

The case studies included are as follows:

- **Case Study 1: Leah's Story**

  Leah is a 14 year old young carer who helps to care for her 8 year old brother who suffers from a rare genetic disorder called Peters Plus Syndrome.

- **Case Study 2: Alfie's Story**

  Alfie is a 12 year old young carer who supports his mum through bouts of depression.

- **Case Study 3: Natalie's Story**

  Natalie is a 12 year old young carer who supports her mother (who is almost blind) to look after her 2 year old sister Victoria who suffers from hydrocephalus (water on the brain) and has severe learning difficulties.

- **Case Study 4: Grant's Story**

  Grant is a 16 year old young carer who cares for his mother who suffers from chronic depression and agoraphobia, along with his brother who has attention deficit disorder.

The original case studies can be found on the following website:

www. carers.org

Case Study 1: Leah’s Story

I am a 14 year old young carer. I care for my brother Max who is 8. Max suffers from a very rare genetic condition called Peters Plus Syndrome.

This condition mainly affects his eyes but he has many health problems. He has dwarfism and will have for the rest of his life. He is about the size of a 2-3 year old at the moment. Nobody can tell but he probably won’t grow much bigger. He was born with a cleft lip and palette and a malfunctioning kidney so he had half a kidney removed shortly after birth. He cannot eat so he is fed via gastrostomy (a surgical opening through the abdomen; a feeding device is inserted through this opening into the stomach. He also has a delayed mental age of about a 4 year old. He is incontinent so he has to wear a nappy.

Throughout his life he has had over 40 operations and there is still more to come. Most of these operations are on his eyes because he has Peters Anomaly of the eye. He is registered blind but he does have some basic vision.

When I get up in the morning I have jobs to do. I get myself ready and help my mum get Max and my two younger brothers ready for school. Max is very dependent so he requires 24 hour care and has to be helped doing the simple things.

At school it is sometimes hard to concentrate. Max has to go to hospital a lot and it is usually a long way from home.

“I always worry about him but I know he is being looked after. I can’t really talk about it with my friends because they don’t really understand what it is like being a carer”.

When I get home, my mum is usually out picking my two younger brothers up from school. I have to get home to look after Max. He comes home on a minibus supplied by the school so I don’t need to worry about getting to his school which is good. When he comes home I have to change his nappy and his clothes and put him on his feed.

My mum is a single parent so it can be hard for her to get all the jobs done. If my mum is busy I will cook a meal and I will give Max or the other boys a bath.

The house also needs to be tidied up because if something is left on the floor Max wouldn't see it and would trip over.

My mum doesn't have a car so it is hard for us to out as a family. If we do go out for the day it is quite rare and it also needs a lot of organisation because Max has to have a lot of things with him whenever we go out.

Case Study 2: Alfie's Story

Alfie, 12, does a lot of practical things to help his mother, Tracey, who suffers from bouts of depression.

He goes shopping four times a week and helps with the cleaning, washing and tidying. But he knows that his main job is even more important. 'It's to make her smile and keep her cheerful', he says.

He has learned to recognise the signs of his mothers black mood coming on. Alfie asks me if I'm feeling OK and though I say I am, he knows I am not and starts doing things for himself' says single mother Tracey, 42.

"I know he needs to be cared for as a child but instead it is him keeping me going with kisses and cuddles and trying to make me laugh".

"He'll say: 'Come on, mum, let's have a game of cards.' He knows he can't cheer me up fully inside but he can put a smile on my face for ten minutes once a day. He's my teddy bear".

Alfie confesses he 'gets a bit fed up' when his mum is sinking into a depression which renders her unable to function for several days but he happily takes on the chores. 'I know she needs time to herself to go for a walk or visit my nan and I don't mind doing things in the house'.

Case Study 3: Natalie's Story

12 year old Natalie's day starts early. She gets up first, has her bath then runs another one for her two year old sister Victoria who suffers from hydrocephalus (water on the brain) and has severe learning difficulties.

Natalie then helps her mother Anna, who is almost blind, to bathe the little girl, taking particular care of the tube inserted in her head to drain away the liquid.

"I dress my sister and put her nappy on, make her breakfast cereal and prepare her milk and her nappies and wipes for the day. I show mum where everything is so she can cope while I am at school before I leave the house at eight".

"After school I cook the tea, maybe rice, noodles or chips and sausages. I do some cleaning and laundry and wash the dishes. I help my mum put Victoria to bed, get her nappies ready and put her milk by the microwave so all mum has to do is push the buttons to warm it up. At the weekend I go shopping with mum because she can't see what to get without me.

"It keeps me very busy", says Natalie. I have time to do my homework but not for anything else. I'm ok with it. I like caring for mum and my sister because I get to play a lot with my sister and to talk to my mum all the time so I feel very close to them. I like cleaning up too because then everything looks good and it makes my mum happy.

"Sometimes I wish I could go out with my friends or have them to stay but I don't feel jealous of them. I think I am a bit more grown up than them. They don't look after their parents. Some of them don't even know how to cook. I don't tell them I can't come out with them because I am a carer. I just say I am busy".

"I'm not sure why but I think it's because I'm afraid they might make some comments about my family and I don't want that".

After spending many months on the waiting list, Natalie began attending her local Carers' Centre every Friday evening two months ago and says it has made a huge difference to her life. She plays sports such as tennis, basketball, football and cricket and does indoor activities such as arts and crafts and cooking.

But perhaps the most valuable thing is that she meets other children in the same position so she doesn't feel "different" or have to hide who she really is. There are adults to whom she can turn for advice or support, both practical and emotional, and readymade friends she can talk to if it's all getting a bit much.

She also gets a brief break from her family responsibilities in which she can just enjoy being a 12 year old child. "I get two hours to myself, relaxing and not looking after anyone", Natalie says.

Natalie became the linchpin of the family two years ago when Anna, 34, started losing her sight. "I rely on Natalie a lot, even for simple things like telling me when the clothes I have put on are not quite clean or if I've put something on inside out", she says.

"I have been surprised at how good she is. I wish she did not have to do so much but she never complains. She is really understanding, saying to me, 'Mum, it's not your fault you can't see'. I could not manage to look after Victoria without her. She is a gift".

Case Study 4: Grant's Story

Grant is a 13 year old caring for his younger brother Liam who was born with pneumonia and has developed several problems since then.

Sometimes it all gets too much for Grant, when he's sitting in school trying to concentrate but can't stop worrying about what's going on at home.

That's when he uses the 'time out card' that his local Carers' Centre gave to his school, so his teachers would understand when he just has to get out of the classroom to collect his thoughts.

Having someone else explain what you are going through is a relief to a sensitive 13 year old like Grant, who often gets emotional about his younger brothers and sister. If it had not been for the Carers' Centre, children like Grant would feel alone, scared and unsure where they could get help.

His brother Liam, 12, was born with pneumonia, developed a bowel disorder and now has an ileostomy and takes supplementary food through a tube in his stomach. He has learning difficulties and is partially deaf.

The boys live with their dad Andy and stepmum Danielle but at times Grant takes charge of changing his brother's ileostomy bag, keeping the tube clean and giving him nutrition.

His step-sister Jessica, aged four, has arthritis and his one year old stepbrother Joshua needs regular physiotherapy. His dad has recently had major back surgery and is due for more.

Not that Grant minds caring for Liam: "I protect him when we are out together. He can walk but he's a bit slow and he doesn't know about traffic. His hearing difficulties can make things hard. At home I keep him entertained by playing on the playstation or watching videos with him. I am his best friend. I also help with the chores like doing the washing up".

"What I like about being a carer is knowing I am different. It makes me feel good because I am helping someone. I don't resent the time I give to looking after him because he is special to me and it's not his fault that he is ill".