

Getting It Right For Young Carers

The Young Carers Strategy for Scotland: 2010 - 2015 Summary





Introduction

This summary of 'Getting It Right For Young Carers' is for you as a young carer, your friends, relatives or for anyone else you think would like to read it. Although this is a summary, it is 28 pages long – that is because there are so many issues about young carers. The summary includes a massive 31 quotes from young carers of all ages and in all caring situations. The quotes are in speech bubbles – just look at them for the best summary of what young carers think and say.



The Scottish Government and the Convention of Scottish Local Authorities (who represent the 32 local councils in Scotland) have worked together to produce a new strategy for those of you who are young carers.

The strategy is called *Getting It Right For Young Carers*. This booklet provides a summary of the strategy's main points.

Many other organisations who work with you have helped to produce *Getting It Right For Young Carers*. Some of you have also helpfully contributed, and your quotes are included in this summary.

By 'young carer' we mean "a child or young person aged under 18 who has a significant role in looking after someone else who is experiencing illness or disability".

This means that you are a 'young carer' if you help to look after a parent, grandparent, brother or sister, or another relative, or a friend or neighbour, who is unwell, or is disabled. You will be a young carer if you are helping to look after someone who has a mental health problem, or who is having difficulty as a result of their use of illegal or prescription drugs or alcohol.

A young carer is a young person who looks after someone who is ill, and cannot manage to look after themselves and is sometimes in hospital.

Sandra, I I years

As a young carer I know that I have to look after my mum and help her to get better and I know that she is not able to do things for herself.

Fiona, 9 years

The Care 21 Report; The Future of Unpaid Care in Scotland www.scotland.gov.uk/Publications/2006/02/28094157/0

Some children and young people like being young carers. You have a good role within the home, which allows you to show your commitment and love to a family member. It can help you to gain skills and to become more grown-up and independent.

However, we have produced *Getting It Right For Young Carers* because we are concerned that caring can sometimes have a bad impact on your lives, for example, on your health and well-being, opportunities and development.

Getting It Right For Young Carers highlights the importance of recognising the rights that all children and young people have under the United Nations Convention on the Rights of the Child (UNCRC).

Being a young carer, there is no time to have a childhood. It's like living in "dog years," you grow up much quicker than everyone else your own age. I feel as if my life has been much longer than it actually has, I have brought up a family from the age of 8.

Siobhan, 19 years

We know that the demands that you face can sometimes deny you your UNCRC rights. In particular, the right:

- to be protected from discrimination (article 2)
- to form and express your own views (article 12)
- to life, survival and healthy development (article 6)
- to spend time with friends (article 15)
- to enjoy opportunities for leisure and to relax and play (article 31)
- to education (article 28 and 29)

Getting It Right For Young Carers says that staff in all organisations need to think about what they can do, and do what they can, to promote your rights.

Many young people who are providing care do not see themselves as 'young carers.' You may have been one of these young people yourself. You are often not seen as 'young carers' by the organisations that support you, or that could provide you with support.

Getting It Right For Young Carers has also been written to help staff and agencies working with children and young people - in schools, health services, social work and other settings - to be much more aware of the issues affecting you.

Getting It Right For Young Carers is also very relevant to those health and social care staff supporting adults affected by disability, illness or who have problems with alcohol or drugs. This is because we see that the best way to support you is to take away some of the caring you do, by providing better support to the person you are caring for.

By raising the awareness of staff, such as social workers, health visitors and teachers, they will better understand the issues affecting you and will be more able to identify those of you who provide care. In turn, this will help to make sure that you are given the support that you may need.

So, while we see the good things that caring can bring, the key aim of the strategy is to support agencies to take away from you any caring role that is too much or not appropriate – things that may have a bad impact on your health and wellbeing. In doing so, you will be supported to be children and young people first.

In producing *Getting It Right For Young Carers*, we have linked it closely to the Scottish Government's *Getting It Right For Every Child (GIRFEC)* programme, which is being taken forward across Scotland.

GIRFEC is an important new approach that all agencies are encouraged to use. It helps to make sure that all agencies work more closely together to support children and young people to have a better life.

GIRFEC provides an assessment tool that staff in all agencies can use to gather information about a young person. It puts the child at the centre of the process and identifies and builds on the support that they may already get from their family and local community.

GIRFEC involves the child in the assessment process and then in the process of developing an action plan. As more and more agencies start to take on the GIRFEC approach, you will benefit from these agencies working more closely together to provide better and earlier support to all young people who need it. This will include you as a young carer.



Profile of Young Carers

Some studies think there are over 100,000 young carers in Scotland. However, different studies estimate different numbers. This is because there are different definitions of a 'young carer' and because not all services keep information on the numbers of young carers they are working with.

In 2001, the Census in Scotland identified 16,701 young carers. This number is much lower than other estimates. This is probably because the Census questionnaire is filled in by adults and because many of you are not identified or do not see yourselves as 'young carers'. The next Census will be in 2011 and it will be interesting to see how many 'young carers' are identified 10 years on.

People who plan services and provide support need to know more about all young carers and research and studies can help with this.

One major study² found that: many of you are living in lone parent families; your average age as for someone with a physical health problem; just over half of you are caring for your mothers; a third of you are caring for a brother or sister; many of you are providing emotional support, in addition to more practical help and personal care; one in ten of you are caring for more than one person; half of you are caring for 10 hours or less, one third for 11-20 hours and 16% for over 20 hours; caring can start at an early age and continue for a long time.

While all of you are individuals, you may also have have other particular challenges. For example, some young carers are lesbian, gay, bisexual or transgender, others come from minority ethnic communities and some live in rural areas. You are dealing with the normal demands of growing up, as well as the demands of caring, and sometimes also with other demands and pressures.

Being a young carer
means I can make sure my
mum's ok, and I can feel proud of
myself for ensuring she's safe and
stable. You get to feel proud and like
you're really making a difference to
someone in a good way. You learn skills
about how to be independent and be
able to function when I move out.
We are more understanding and
accepting of the problems faced
by others.

Rachel B, 17 years

The Effects of Caring on Young Carers

The Good

We have said that caring for a family member or friend with a disability or illness can be a good experience. Here is more detail on that.

By helping in the family, you can feel more valued and included. What you do can also give you greater responsibility and can build up your selfesteem. Providing care can also make you more mature, more confident and more able to deal with problems.

Caring can also help young people gain skills in managing money, looking after the home, caring for other children, making appointments and dealing with health and social care services.

The Bad

When you have to take on too many caring responsibilities, or carry out caring roles that are not appropriate, this can be bad for your health, well-being, safety and development.

While all of you will deal differently with the challenges and pressures you face, some possible effects of caring are summarised below:

School/College

Caring can place demands on you that affect your education. This can result in problems with attendance, being late for school, not being able to do homework and having difficulty concentrating in class.

This can affect how well you do at school

Sometimes teachers can help a lot as they know you are a young carer and they can help you to catch up with your work, but sometimes they do not know you are a young carer and I do not like to tell anyone as they sometimes think you are strange.

Catriona, 13 years

Sometimes I sleep on the couch in my sister's room to give mum and dad a break. It's hard to sleep because I'm afraid she'll stop breathing. It's hard to cope with school the next day cause I'm shattered.

Amy, 12 years

I miss a lot of school time because I am tired as I may have been up helping my mum with her tablets during the night.

Roberta. 10 uears



You can't really tell people about your home life, it's kind of a "taboo" subject. Most of us don't receive help until we're at breaking point. I don't get to see my friends as much as I'd like to, and have to make really bad excuses why I'm upset or can't go out. Plus I'm more tied to what I can do and where I can go for my own life.

Rachel B, 17 years

I want to know if I'm going to get epilepsy. My mum has lost teeth and has bruises all over from when she falls. No one can tell me if I will. I just try not to think about it all the time, but it's hard.

Health - Physical and Mental

The demands of caring can affect your physical and mental health. For example, helping to lift and move someone who cannot easily move themselves can, over time, cause neck and back problems and affect your physical development.

Taking on responsibilities that would normally fall to an adult can put a lot of pressure on you. This can sometimes mean that you may suffer from depression and stress. As you can't always join in

with others the same age, you can feel 'different'. You may be bullied. The pressures you are under can sometimes mean you get into trouble. You feel more alone and you may keep more secrets about your home life.

You often have to deal with a lot of worry about the health of the person you are caring for. You may be scared that you might have the same health problems when you are older.

When you suddenly have to take on a caring role, or when this ends suddenly, it can be very difficult for you to cope with.

If you are living in a family where your parent or other relative misuses alcohol or drugs, you may not get positive support and you may have to look after yourself. You may not eat that well or you may miss health checks and appointments at the dentist, which can affect your own health.

When my dad died I lost my home, my routine, my way of doing things and my important role in the family.

Erin, 13 years

My dad was the main carer for my mum, even though he didn't keep well himself. He died suddenly and I became the main carer for her. She suffers from epilepsy and depression... I was coming up for I 7 and studying for my Highers... I was under enormous pressure. I was at my wits end and felt like I was drowning under all the pressure.

Caitlin, 17 uears

Social

The demands of caring can limit your free time and the chances you have to meet up with friends.

I cannot go out and play with friends because I have to help my dad and my little brother who has autism and he is not able to tell my dad what is wrong.

David, 14 years

Money

Many of you live in families that do not have a lot of money.

This may be because you live with a disabled adult who is less likely to be working and more likely to be relying on benefits. Or, if you have a brother or sister with a disability, your mum or dad may have had to give up work to be a full-time carer.

In families where parents are misusing drugs or alcohol, you are more likely to have financial problems. This can stop you from having your most basic needs met.

Those of you who are older may also lose out on benefits and opportunities because of your caring responsibility.

My problem is that I
had to drop out of 5th year at
school to look after my mother.
I get no benefits as I am under I 8
so I am not entitled to Carer's Allowance
or Income Support, as I still live with
my mother and they say I am her
dependent. But if I moved out and stopped
caring for my mum, I would be able to
claim benefits and rent too and also she
would need a lot more support from
outside. So by carrying on caring I
am saving the government a lot
of money, but I don't feel
supported.

Andy, 17 years

Neglect and Abuse

In some situations some of you will not be looked after properly or will be at risk of harm.

One study³ showed that these risks are greater when a young person: lives with a parent who misuses alcohol or drugs; lives with a single parent; doesn't have opportunities to have lots of support from friends and others; has a lot of stress in their family life; doesn't have anyone they feel they can turn to; lives in a family where there are health worries, financial problems or housing issues.

Some of you may be living in these kinds of situations.

Everything was fine when my mum wasn't drinking, but when she got drunk it could be for weeks at a time. My brother had to steal money out of her purse to get us something to eat out of the chippy. We were only weans, but we couldn't tell anybody in case we got taken into care.

Stephen, 12 year

³ G. Armstrong "Young Carers' Health and Well Being; A Pilot Study".

Identifying Young Carers

Many children and young people do not see themselves as 'young carers'. Many are not identified as such by the services they are in contact with.

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Over the next few years, all children and young people in Scotland will get support, whether or not they have been identified as a young carer. This is quite a new Government programme, which is called *Getting It Right For Every Child*.

Many of the young carers who attended the Scottish Young Carers Festivals in 2008 and 2009 said that they felt that teachers, health service staff and social workers could do much more now to identify and support them.

Teachers

Teachers may be able to pick up that someone is a young carer through their day-to-day contact with their pupils, or when taking registration, or providing guidance support – also when looking into concerns about attendance or behaviour, or how well pupils are doing.

There is a new curriculum which will begin in schools on 2010, called the *Curriculum for Excellence* which will encourage teachers to think more about why some pupils might not be getting on as well as they should at school.

There is also a law called The Education (Additional Support for Learning) (Scotland) Act 2009 which says that if you are a young carer, you have a right to help you attend school and get on well while at school.

The Scottish Government has given the Princess Royal Trust for Carers funding to help teachers in primary schools to identify and support younger young carers. It is important that very young children get help as soon as possible, so that the bad effects of caring do not spoil their lives.

Staff who work in Health Services

Staff who work in health services are often in a good position to identify young carers. When they are working with an adult who is ill, disabled or who has a problem with drugs or alcohol, they can ask the adult about how their illness or disability affects the children in the family.

It is most likely that you know better than anyone else how the person you are caring for is getting on. However, some of you have told us that when you are a young carer, you are often left feeling frustrated that doctors and consultants don't ask your opinions and leave you out of the plans they make for the person you look after.

Some of the things we have recently put in place which will make this situation better include:

- with funding from the Scottish Government, every area has developed a 'Carer Information Strategy'. This means that health staff are getting training and information about how to identify and support young carers.
- the Royal College of General Practitioners
 Scotland is putting together information on
 identifying and supporting young carers. This
 will be sent to every doctor's surgery in Scotland
 in 2010-11.
- NHS Education in Scotland will be looking at how they can raise awareness of young carer issues in staff training.

GPs and doctors haven't taken any consideration into my point of view of the illness despite the fact I help my parent with this illness 24/7. It's frustrating.

Rachel B, 17 years

I'm 17 yet when my mum was in hospital no one would discuss my mum's situation with me. I'm her main carer and have been since I can remember. It's humiliating and frustrating not being involved in decisions about my mum yet I am considered old enough to care for her.

Social Workers

Because social workers often go into people's homes where there is illness and disability, and sometimes other problems, they are well placed to identify and support young carers.

It is important that social workers make sure that the plans they make for an adult do not depend on you carrying out tasks you do not want or are not able to do or which are just too difficult or personal.

They should also recognise that as young carers, you need to be kept informed and involved when you can be.

It feels like I'm
invisible when people
(agencies) come into the
house. They don't talk to me.
I care for my mum all the time,
but they don't think they
should be telling me
anything. It makes me
really angry.

Andy, 17 years

Others

All organisations working with children and young people need to recognise that a number of you will be young carers. This applies, for example, to: youth clubs, after-school clubs; other child care organisations; churches; and the emergency services.



Young Carers Assessment – What do you need to help you?

You have a legal right to ask for an assessment. This can be of great help to you to get the information and support you need so that you are not doing things which are too difficult for you.

You can ask anyone in your school, at your health centre, or any social worker to do this for you. They may not do the assessment themselves, but they should be able to put you in touch with someone who will work through this with you.



Supporting Young Carers

Young carers can be supported in a number of ways – in this section, we look at some of them.

It is best if support can be provided to all young people before they begin to experience difficulties If you are a young carer, this means it is important to identify and support you before the caring role begins to have a bad effect on you.

Support to the person you care for

The best way of making sure that you are not having to do too much caring is for health and social workers to provide good quality care and support to the person you care for. Staff should also ask about what you do for the person you look after, and ask if you need help too.

Social workers
helped me and my
brothers, but not my mum.
Which means if
you don't help her...you
aren't helping me at all.

Young Carer, Scottish Young Carers Festival, 2009

Young Carers Groups

There are nearly 50 young carers' groups across Scotland. They are in touch with about 3,500 young carers. These young carers' groups all meet together four times a year and call themselves the Scottish Young Carer Services Alliance (SYCSA).

The type of things a young carers group does includes:

- emotional support and counselling, through talking to you as an individual;
- group activities, which provide chances to meet other young carers and try new things; and
- "time out" from caring and organising short breaks and holidays that many of you might otherwise not be able to have.

I honestly
say I love my group so
much and it has helped me
to feel really confident. I also
feel as if I can be more open
about my situation and feelings.
I absolutely love the staff and the
girls and I know for certain they
will always be my friends. I feel
comfortable with them and we
have hundreds of laughs and
lots of memories.

Some young carers' services also provide training, support to the whole family, advocacy support, or work within schools.

You have told us very good things about the support you receive from your young carers' groups, and about the difference this can make to your life. One thing which seems really important is how good it is to be able to be in touch with other young people in a similar situation.

You are also very keen about the support you receive from the workers in these groups and about their commitment to supporting you.

Young carers' groups are working very hard to support as many young carers as they can. The SYCSA is helping to support these groups: to develop the work that they are doing; to share information and resources; to raise other people's awareness of young carers; and to make sure that they work closely with other services like school which can help you.

Many young carers' groups have to work hard to get funding so that they can continue to do the work they do. With all the talk about services being cut, it is also important that young carers' groups show that they provide good value for money.

The Scottish Government will work closely with the Scottish Young Carer Services Alliance to promote the work of young carers' groups, so that people understand what they do, and use them properly.

They offer support and opportunities to discuss the issues we face on a daily basis. They help us a lot with family problems.

Young Carer, Scottish Young Carers Festival, 2009

Always have that shoulder to cry on. First person I would talk to about anything. They are awesome.

Young Carer, Scottish Young Carers Festival, 2009

Support to Young Carers in your School

You have told us that head teachers, teachers, guidance teachers and support staff in schools can play an important part in identifying and supporting young carers.

Unfortunately, sometimes schools don't recognise how your caring responsibilities can affect your attendance, concentration, performance and behaviour. Sometimes, the way teachers react to this is not helpful, and they might discipline you rather than give support.

In my school they did understand my situation, because I talked to my guidance teacher. After that they helped me and my brothers to get transport to go and see my mum in hospital. My registration teacher was the best.

Teachers could be more understanding about our needs.

Young Carer, Scottish Young
Carers Festival, 2009

Young Carer, Scottish Young Carers Festival, 2009

Teachers should take time to think about what we do at home and ask us if we are ok sometimes.

Young Carer, Scotlish Young Carers Festival, 2009 There are many different ways that schools can support you to help you cope with the demands of education combined with the demands of caring. These include:

- providing support for your learning and helping you to use equipment like PCs, for information
- making sure young carers are included in plans affecting all pupils
- making sure that detention does not clash with caring responsibilities
- giving bus passes to help you take part in activities after school
- allowing young carers to keep mobile phones switched on in class
- introducing you to the local Young Carers Project for support
- making arrangements for young carers arriving late at school
- giving extensions to homework deadlines
- providing homework help classes
- making your timetable flexible enough to suit you.

Information and Advice for Young Carers

You told us that you need good quality information and advice.

Here are some things which we think might help:

If you think you are a 'young carer,' you could go to **www.youngcarers.net** run by the Princess Royal Trust for Carers. They provide information as well as discussion boards and chatrooms that allow you to share experiences, post messages, ask questions and find support.

Young carers' groups can also help you to get good information and advice on a range of subjects: health; the law; drugs and alcohol; personal safety; children's rights; activities; employment; benefits; and on looking after people with different health conditions.

As many young people who provide care might not call themselves a 'young carer' it is important that there is information about this available on other sites which are used by young people. www.youngscot.org provides this, as well as links to other important sources of information.

Good information can help you understand the world around you a little better, let you know about the opportunities which are available, some of the risks you might face, your rights, and the groups and services that can support you.

Young carers have also told us that doctors could do better at providing them with information and advice.



Later in 2010 or in 2011, all doctors in Scotland will receive information that will raise their awareness of young carers, the issues they face and the need to support them.

Information for young carers will also be available sometime soon on an NHS website. The 'Carers Information Zone' will provide advice on caring and information on where young carers can get support.

Advocacy

All children have the right to have their voice heard when decisions are being made which affect them. There are many situations where your views should be taken into account. Sometimes you need other people to speak up for you, and represent what you think. This is called advocacy.

The Scottish Government is carrying out work to make advocacy support for children better. This will consider the particular needs you may have as a young carer.

Young Carers' Health and Well-being

Sometimes because you are caring, you may feel unwell, tired, upset, angry or emotional.

Young carers' groups can help with some of this. They give information and advice on your health and on how you might be feeling, arrange health checks and doctors' appointments and they can provide support and advice for you when you go to see your doctor. They can also give you advice and help about how to keep healthy and about personal safety.

Workers in these groups will also listen to you when you want to talk about some of the problems you are having. They will help you to say what you think about things and help you to make sense of your situation.

The Scottish Government has funded a Mental Health Development Worker. This person will make more information available for young carers who care for someone with a mental health problem. She will also provide support to improve young carers' mental health and well-being by getting more expert people involved.

Breaks from Caring

To enjoy your childhood, you need to be able to take a break from caring and get away from the responsibilities for a while.

Many of you may be feeling quite alone and feeling that you can't talk to friends about the situation at home. If you are able to attend a young carers group, you can meet other young people who are also young carers, and you can also take part in activities to help you feel better,

and get some time out of the house. Some young carers' groups organise 'residentials', and even holidays. You could also try joining a youth or sports club in your area. You might need some help to do this, and this is the kind of thing you could mention if anyone asks you if you need any help because you are a young carer. Sometimes arrangements can be made for someone else to go into your home to give you some time out.





Young Carer Training

You might feel that you need some training to help you stay safe, and look after yourself when you are caring for someone. You might need some help in building your confidence, or in trying to cope with feeling stressed.

Training can provide knowledge and skills to help you understand the condition of the person you care for and how to provide them with assistance. However, we do not want to train you to do things that you shouldn't really be doing at your age, things which are not right for you or which are dangerous. We just want to make sure that you are safe.

Telecare

Telecare is the term used to describe the use of technology to provide support to people with disabilities, frailty or health problems in their own home. These are things like bracelets and necklaces which have a button to let someone know they are in difficulties. The Scottish Government has invested £20 million in telecare in recent years.

Getting It Right For Young Carers says that more should be done to explore how telecare can help young carers.

Young Adult Carers

Young carers aged between 16 and 25 years can face particular challenges. At a time when others their age are leaving school and making plans for employment, training and education, young adult carers often have to deal with demands, responsibilities and emotions that limit their future opportunities.



Young adult carers may, for example:

- be committed to continue to provide care, but may not be able to tell others, including careers advisors and jobcentre staff, that this is why they are not making other plans;
- feel that they have to continue to care, or professionals may assume they are going to;
- be anxious about leaving home because
 of worries about the person they care for or fear
 that a younger brother or sister may have to
 take on caring responsibilities; and
- be desperate to leave home at the earliest opportunity, but not have the knowledge and skills to deal with the challenges this brings.

Many young adult carers face these difficulties when their young carers' group is no longer able to support them, either because they have a high demand for places or because they aren't funded to work with young people over 18 years.

Young adult carers also don't feel that they fit in to the services provided by Carers Centres for adult carers.

Some young carers' groups have been able to create groups for older young carers.

The Scottish Government and its partners are also delivering a number of services and projects that try to ensure that young people who might otherwise be left out are able to access training, employment or further education.

When working with
the staff at the project
I feel it is a relief because
I know I can off-load and
anything I say is in
confidence. I feel I am
getting more opportunities
in various different areas
in my life.

Laura, 19 years

Recognise we need help until 25 years. Young Carer, Scottish Young Carers Festival, 2009

I have got my
confidence back since I
became involved with the
project. The only thing I have
found challenging is to get up in
the morning and leave my mum
when she is upset. I have enjoyed
meeting new people and seeing
my worker because she is
very nice and boosts my
confidence.

Pauline, 17 years

Summary of Action Points

The long version of this strategy, *Getting It Right For Young Carers*, sets out all the Action Points to be taken forward over the next five years. There are a lot of actions, some to do with research, gathering data, encouraging others to identify and support young carers and so on. Some of the actions you may find of most interest are:

 The Scottish Government will give the Princess Royal Trust for Carers funding of £ I 50,000 to deliver a Scottish Young Carers' Festival in 2011

- The Scottish Young Carers Services Alliance will work in partnership with LGBT Youth Scotland in order to develop information, advice and support for LGBT young carers.
- By 2012, local authority Education Services will wish to look again at their policies, procedures and approaches for identifying young carers in schools.



- The Scottish Government will work with the Scottish Young Carers Services Alliance to produce a practice guide on young carers for teachers and schools.
- In 2010-11, the Scottish Government will work with the Royal College of General Practitioners Scotland to provide guidance to all GP practices on young carer identification and support.
- In 2010-12, NHS Education for Scotland (NES)
 will review training, education, and learning
 modules for working with young carers; identify
 core competencies for NHS staff in identifying
 and supporting young carers; and identify
 packages and materials to be included in training.
- From 2010 onwards, the Scottish Government will work with NHS Boards to ensure that identifying and supporting young carers is included in workforce training.
- From 20 I 0 onwards, the Scottish Government will promote this strategy with Alcohol and Drug Partnerships to help support young carers affected by parental substance misuse.

- By 2012, local authority Education Services will wish to review the approaches they have in place for making sure that young carers are supported in school and to make sure that they are not disadvantaged because of the impact of their caring roles.
- The Scottish Government will consider the needs of young carers in its work on developing advocacy support to young people.
- The Scottish Government will continue to support local authorities and their partners to implement I 6+ Learning Choices. This will include working closely with Skills Development Scotland in its role as the national provider of careers information, advice and guidance.
- By 2011, the Scottish Government and relevant partners will develop a "Young Adult Carers Action Plan".



IMPORTANT

If you have been affected by anything you have read in this short version of 'Getting It Right For Young Carers' – especially around issues of neglect and abuse – then please get in touch straight away on the following:

Child Line - 0800 1111

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