

CORNWALL

**MULTI-AGENCY
STRATEGY**

FOR YOUNG CARERS

2010 – 2013



Foreword

When we hear about “carers”, we invariably think about adults looking after someone. Rarely do we stop and think about the contribution children and young people make to others in need of care. In the Count Me In 2001 census, there were 175,000 children and young people in the UK providing some care to family, friends or neighbours, the majority caring up to 19 hours per week, some for between 20 - 50 or more hours per week. In Cornwall we are aware of about 420 Young Carers but we also know there are many more we are not helping as well as we could and should be.

Caring can be a positive experience, helping to foster maturity, independence and strengthening family ties. Children and young people themselves value the contribution they are able to make. It is a tough job and Young Carers deserve our support. Young Carers often face additional challenges that can impact on, for example, their school attendance, educational achievement, their physical and emotional health and how they can be at risk of social isolation and bullying. Making the transition to adult life and independence can be particularly difficult.

“I worry so much about my mum, I can’t concentrate at school, I get in trouble for being late and I get bullied. None of the doctors bothered to explain to me what is really wrong with her. I love my mum so much and I do everything I can to help her, but people don’t understand. It’s no joke.”

(Young carer aged 13 in a lone parent family)

In Cornwall, we believe that “Young Carers Matter” too and this strategy takes forward the themes of the National Carers Strategy: “Carers at the heart of the 21st century families and communities” 2008. It is essential that Cornwall Council, Health Trusts and all partners, both in the statutory and voluntary sector, work together to support this vulnerable group of children and young people to achieve their aspirations, make informed decisions and fulfil their true potential and this strategy is based upon the commitment they have made which reflects the vision set out in the 2008 National Strategy:

“...children and young people will be protected from inappropriate caring and have the support they need to learn, develop, thrive to enjoy positive childhoods and achieve against all the *Every Child Matters* outcomes.” (The National Carers Strategy 2008)

Councillor Neil Burden
Cabinet Member - Children’s Services

Councillor Armand Toms
Cabinet Member - Adults

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1. Introduction

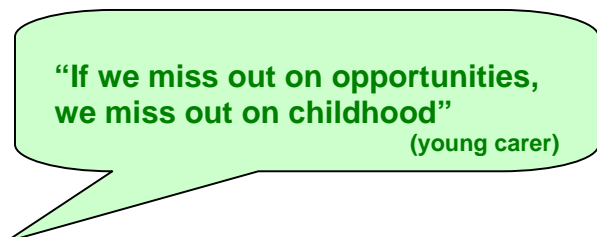
Young Carers are young people (up to the age of 18 years) who are affected by the illness or disability of a family member and who provide them with care and support. Young Carers support family members who have physical disabilities, learning disabilities, mental ill health, and problematic drinking and drug use. Young Carers will often also be responsible for a great deal of their own care.

Many young people with caring responsibilities do not consider themselves to be Young Carers; they merely see themselves as supporting another family member and doing what anyone else would in their situation. This can mean that their role and their needs are hidden and they do not receive any support unless the situation reaches crisis point.

Caring responsibilities cannot not be assumed to be a problem. Many Young Carers are reluctant to give up their responsibilities as they are pleased to help and are proud that they are able to provide support. Young Carers must be supported in their caring role for as long as they wish.

However where the level of care being provided is inappropriate this can result in isolation from peers, reduced self-esteem, poor educational attainment, and limited aspirations. It is important to consider not only the type and level of caring, but also the actual and potential impact on the young person and where this is considered to be negative it would be seen as “inappropriate”. ‘Inappropriate caring responsibilities’ are not defined by the National Carers Strategy. It is dependant on the family circumstances, and the views of the Young Carer need to be taken into account.

Support to Young Carers in Cornwall has developed over the last fourteen years, primarily through the Cornwall Young Carer’s Project which is valued and appreciated by the young people and their families. There is now a need to broaden the definition of Young Carers, scope the level of need and offer a relevant range of services, and co-ordinate the efforts across Cornwall.



**“If we miss out on opportunities,
we miss out on childhood”**

(young carer)

2. The Vision for Cornwall's Young Carers Strategy

The overall outcome of this strategy is to ensure that Young Carers are recognised and valued, receive support for their caring role, and are safeguarded against taking on responsibilities which prevent them achieving their full potential.

Our vision is that children and young people will be supported in situations where they take on caring roles to enjoy positive childhoods and achieve against all the *Every Child Matters* outcomes:

- ✚ **Be healthy:** Enjoy the best physical, emotional, mental and spiritual health and development, so that they feel good about themselves and their lives
- ✚ **Stay safe:** Be safe and protected from harm within their families and communities
- ✚ **Enjoy and achieve:** Realise their ambitions, enjoying and achieving in all areas of life
- ✚ **Make a positive contribution:** Take an active part in positive opportunities presented in all areas and stages of their life and the life of the community, and be valued for their contributions
- ✚ **Achieve economic well-being:** Be actively protected from discrimination in order to live free from poverty and hardship

We aim to achieve this by:

1. Ensuring that a Young Carer is seen as a child/young person first.
2. Listening to Young Carers and their families and recognising that they are the “experts” on their situation.
3. Identifying and reducing the incidences where the reliance on the caring role provided by a child or young person impacts negatively on their well being and life chances and protecting them from harm.
4. Reducing the incidence of families with unmet care needs.
5. Ensuring that all professionals are aware of what it means to be a Young Carer and work to improve the outcomes for Young Carers.
6. Encouraging Young Carers and their families to come forward for the help they may need.

7. Ensuring all agencies coming into contact with families carry out their duty to safeguard children and young people, have the knowledge they need to identify problems early and arrange for effective support to be provided for the young carer and the person being cared for.
8. Ensuring full access to current range of services and developing other services as required that meet the diverse needs of Young Carers, in partnership with Young Carers and their families,
9. Delivering better, joined up, whole family support to families affected by illness or disability.



3. Who are Young Carers?

Young Carers are young people (up to the age of 18 years) who are affected by illness or disability of a family member and who provide them with care and support. The person they care for may be a parent, a sibling, another family member or a friend, but need not necessarily live in the same house as them. The care they give may be practical, physical and/or emotional.

The terms “disability” and “long term illness” do not just mean a physical disability or illness, but also cover, for example, mental ill health, learning disability, or problematic substance use, frailty or old age.

Young Carers will often also be responsible for a great deal of their own care.

4. How many Young Carers are there?

The Count Me in Census 2001 identified that within the UK there were at least 175,000 Young Carers, 13,000 of whom cared for more than 50 hours per week. The average age was 12. More than half lived in one-parent families and almost a third cared for someone with mental ill health. This figure is certainly an underestimate as it was based on answers given by parents, with their perceptions of their children's roles and the number of hours they spent caring. The census did not ask about those caring for someone with problematic drinking and drug use. In addition under reporting from families is highly likely as there may be a fear of becoming stigmatised.

The Cornwall Young Carers Project reported in 2009:

- 420 Young Carers identified
- 220 are being supported in some way
- 42% are female
- 58% are male

- 16% aged between 5 and 10 years
- 49% between 11 and 14 years
- 35% aged 15 years plus

- 36.5% care for parent/s with mental ill health
- 38.5% care for parent/s with long term illness
- 14.5% for parent/s with physical disability
- 10.5% care for parent/s with drug or alcohol addiction

This reflects the national picture – 2004 study carried out by Young Carers Research Group at the University of Loughborough.

The work of the Cornwall Young Carer's Project is primarily with Young Carers caring for a parent or another adult in some way. However, it is also important that services are developed to include support for those who help to care for a brother or sister. Young Carers are a largely invisible workforce. The current Cornwall data is accepted to be an underestimate and the scale of the issue and the gaps in support services for these children and their families needs to be better understood. Identification of Young Carers is a key issue to be addressed by the action plan complimenting this strategy and every effort will be made to identify who our Young Carers are, who could benefit from additional support and

the kind of support that would make a positive difference in safeguarding their best interests.

It is difficult to identify Young Carers because:

- Young people who do care for others do not always describe themselves as such, especially very young children.
- Lack of awareness by a professional in contact with that child and/or family.
- Young Carers and their families can be reluctant to be identified.
- Poor information systems for collating data about the number of Young Carers.



5. What do Young Carers do?

The extent and nature of the caring provide by Young Carers varies widely but may include:

- practical tasks such as cooking, household chores, shopping and gardening;
- personal and intimate care including help with toileting needs, washing, dressing and undressing and feeding;
- physical care such as lifting;
- administering medication, changing dressings, giving physiotherapy or assisting with mobility;
- managing the family budget, collecting benefits and prescriptions;
- looking after or parenting younger brothers or sisters
- interpreting;
- emotional support, including observing emotional state, providing supervision, trying to 'cheer up' the person they care for when they are depressed, talking, listening;
- ensuring safety.

“Helping her is just part of life. I don’t really remember it being any different.”

(young carer)



6. The Voice of Young Carers and their Families

At the heart of this strategy is the voice of Young Carers and their families. It is vital that they are key partners in the implementation of this strategy.

Nationally and locally Young Carers have told us:

- They want schools to respect and understand the issues they have to deal with at home and to promote more awareness and tolerance of disability and illness:
- They want health professionals to communicate with them about the medical care of the person being cared for in a clear and simple way, e.g. explain what to expect in the way of illness or behaviour, what to do in an emergency, how best to lift or move someone.
- They want professionals from all agencies to recognise that it is vital to consult with Young Carers and their families because they know their situation best.
- They want all workers to consider all the family members needs, not just one member and to provide flexible services because circumstances can change affecting the level of support Young Carers need.
- They want good information, advice and guidance that is easily accessible and flexible, responsive services.



They have told us about the many ways that caring for someone else affects them:

"I am not sure if I can go (to university) now because it means leaving home and there isn't the support there for everyone else if I go"

"I get into trouble for not completing my homework on time or for being late. Then I get a detention. I just can't win."

"For 5 years my daughter did all the housework, took care of my personal needs including going to the toilet and pulling my wheelchair up and down stairs. I now have direct payments and I feel able to fulfil my role as a parent...now we both have a life"
(Parent of young carer)

"Young people have a right to know what is happening in their family – they should not have to sit outside doors and listen to find out"

"It was when I fell asleep in class that they found out my mum was ill....I didn't used to talk to anyone. I suppose that was my own fault but then, I didn't know anyone was interested."

"It's just something I do. It has to be done and there is no one else to do it." (young carer)

"I quite often go in with my mother when she goes to the doctor but they still don't recognise that I am a young carer and still don't pay attention or give time to that"

"Once, when my mum was ill I was in school and I had an epileptic fit due to stress"

"It's not just the caring that affects you it's the worry of it all."

"Schools need to recognise that our responsibility as carers can affect our education and schoolwork" (Young Carer speaking at Young Carers Festival 2006)

"My children seemed to grow up very fast, the eldest two were playing like mummy and daddy, they were basically being mummy and daddy near the end of my drinking towards me and my other two children, asking if I was alright and basically being really protective of me. They had lot of extra responsibility which they shouldn't have had because they're children... But if the help had been there for me, as an adult, then it would have lightened the load for my children"
'Bottling It Up' 2006, Turning Point

Research with Young Carers has consistently shown negative impacts to several aspects of their lives: namely – their personal life; their social interactions; their physical and emotional health; their educational attainment and their employment opportunities. Indeed, across each of the Every Child Matters outcomes.

- **Their Personal Life**

- Young Carers may have limited horizons and aspirations as a result of their reluctance to leave the family home.
- They are often limited in terms of their opportunities to take part in social or leisure activities.
- A fear of professionals is quite common, with Young Carers and their families often reluctant to share their situation for fear of judgement or the young person being taken into care.
- Young Carers are often forced to grow up more quickly than their peers as a result of their responsibilities, this sets them apart and isolates them.
- Young Carers may feel tension between their own needs and the needs of the person they care for, potentially resulting in feelings of guilt.
- Young Carers may have low self-esteem; this can be compounded where their contribution is undervalued and they are excluded from discussions about the family's needs.

- **Their Social Interactions**

- The differences in life experience between Young Carers and their peers can result in difficulties, causing restrictions on friendships and lack of empathy. Being bullied is a common feature in the lives of Young Carers.
- Isolation and feelings of being an outsider can lead Young Carers to avoid discussion with adults regarding their caring role, resulting in their role going unnoticed.
- Young Carers may also face bullying or other negative treatment due to the type of illness, or condition present in their family. This 'stigma by association' can be particularly prevalent where mental ill health or substance misuse are issues.
- In cases where Young Carers are responsible for their own care, cleanliness and hygiene may be issues.

- **Their Physical and Emotional Health**

- Health problems may develop for Young Carers due to their role. These may be physical health problems, for example back problems brought on by lifting, or mental ill health due to high levels of anxiety and worry.
- The emotional well-being of Young Carers can be negatively affected by seeing a loved one in pain or dealing with behaviour from a family member which may be irrational, unpredictable and hurtful. Bereavement and fear of bereavement can also impact on Young Carers. This can include bereavement for the change in family circumstances following the onset of a long term condition or illness.
- The presence of problematic drinking and drug use within the home can confuse young people's perceptions of safe practice.

- **Their Educational Attainment and Employment Opportunities**

- Many Young Carers leave school with low grades or no qualifications. This can be the result of missing school, not completing homework, or being tired and distracted whilst at school.
- Many Young Carers face major difficulties in making the transition into the world of work, due to low self-esteem, reluctance to leave the family home and qualifications well below their potential.
- Young Carers often have limited access to extra-curricular activities due to their responsibilities at home.
- Caring responsibilities often influence views on the future, leaving some with a perception that further studies beyond the age of 16 are not feasible.
- Many Young Carers use their experience to access employment in the care sector. This must not be seen as the only career option available. Often low self esteem and poor qualifications limit alternative employment prospects.
- Employment opportunities may be reduced due to caring responsibilities and the impact earning a wage may have on the benefits claimed in the household.

7. Why do we need a Strategy?

The research and the voices of Young Carers and their families above tell us clearly we have to improve outcomes for children and young people in Cornwall. It is vital we address these issues and this strategy embraces that challenge.

In 2008, The Children's Society, funded by the Department of Children, Schools and Families published "Young Carers, parents and their families – Key Principles of Practice." These principles are intended to be used alongside legislation and guidance already in place to enable agencies to respond to the recommendations of national policy drivers. Using the Key Principles of Practice will help ensure the best use of resources and promote whole family working.

It will also enable practitioners to deliver best practice based on the five aims of Every Child Matters, within an agreed safeguarding framework.

The six principles:

1. Children's welfare should be promoted and safeguarded by working towards the prevention of children undertaking inappropriate care of any family member.
2. The key to change is the development of a whole family approach and for all agencies to work together, including children's and adult services, to offer co-ordinated assessments and services that are child focused and family orientated.
3. Young Carers and their families are the experts in their own lives and as such must be fully involved in the development and delivery of support services.
4. Young Carers will have the same access to education and career choices as their peers.
5. It is essential to continue to raise awareness of Young Carers and to support and influence change effectively. Work with Young Carers and their families must be monitored and evaluated regularly.
6. Local young carer projects and other services who work directly with Young Carers will provide safe, quality support to those children who continue to be affected by any caring role within the family.

This Strategy demonstrates our commitment to other strategies and plans including the National Carers Strategy: "Carers at the Heart of the 21st Century Families and Communities" 2008, Aiming High, Cornwall Carers' Strategy, Cornwall's Parenting Strategy, the Cornwall Children and Young People's Plan 2009 -2011, and the Local Safeguarding Children (LSCB) and the Safeguarding Adults (SAB) Boards' Business Plans.

In December 2009, a joint memorandum of understanding between statutory Directors for Children's Services and Adult Social Services "Working Together to Support Young Carers" was agreed. Cornwall Children, Schools and Families and Adult Care and Support will adopt this memorandum.

It is important that we develop practice which will enable Young Carers to be identified and for families to feel able to ask for support. Professionals working with a family should consider not just what the young carer does, but why they do it and what impact it is having on their life.

The needs of Young Carers must also be considered within all tiers of Children's Service provision including the Common Assessment Framework (CAF) processes, to ensure that the whole family's needs are being met within a safeguarding framework. The reasons why children undertake levels of care that may adversely affect their well-being and life chances are frequently complex and to resolve them will require a multi-agency approach.



8. Who is this strategy for?

This strategy has been produced for all those who have a responsibility and interest in supporting Young Carers and their families.

This includes:

- All services within Children, Schools and Families
- Adult Care and Support
- Schools
- Health services and professionals in the community and in hospitals
- Drug and Alcohol Action Team
- LSCB and SAB
- Police
- Voluntary sector

9. How will the vision be met?

The implementation of this strategy is a significant task that requires joint working and partnership both within and between the statutory organisations and voluntary organisations.

Some discussions have taken place with Young Carers and their families but this has been limited to date. However, Cornwall Young Carers Project ran a conference in 2009 and a further three road shows around the county to voice their messages about what is needed and these have also informed this strategy.

Their key message is that they want “Professionals to be aware of what it means to be a young carer”. This strategy will be built on a firm foundation to meet the key principles if we ensure that every health, social care and educational professional in Cornwall;

- Is fully aware of the issues Young Carers face;
- Considers the whole family and;

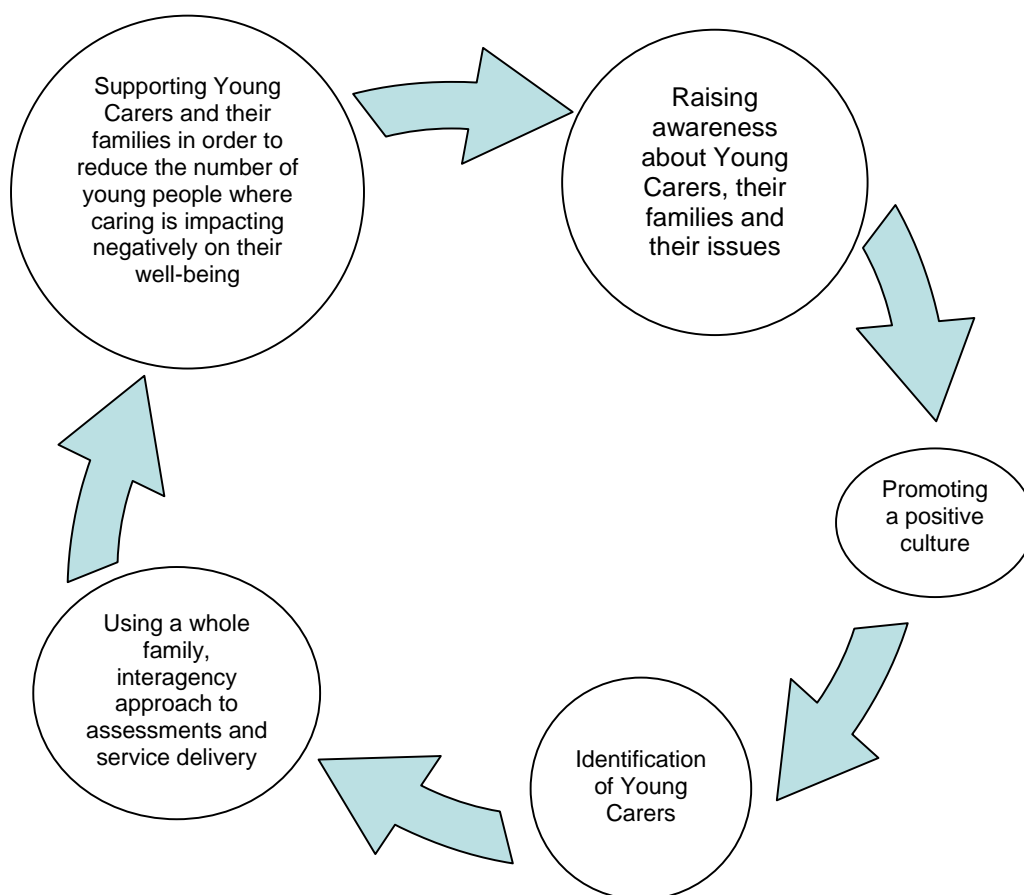
- Ensures that parents are supported in their parenting role.

The active involvement of Young Carers and families in the monitoring, evaluation and review of this strategy and its implementation will be integral to its success.

An Action Plan will be developed detailing 5 specific areas of work:

1. Promoting a positive culture.
2. Identification of Young Carers.
3. Using a whole family, interagency approach to assessments and service delivery.
4. Supporting Young Carers and their families in order to reduce the number of young people where caring is impacting negatively on their well-being.
5. Raising awareness about Young Carers, their families and their issues.

All partners will take forward the action plan in order to carry out their responsibilities in improving the life chances and experience of Young Carers.



10. Governance arrangements

This strategy has been produced on behalf of Cornwall Children's Trust Board and Cornwall Adult Care and Support.

The strategy will be overseen by a multi agency Young Carers Strategic Management Group on behalf of the Children's Trust Board. A Young Carers Strategic Development Manager has been commissioned from Barnardo's for one year to establish and lead a multi-agency Implementation Group in driving forward this strategy and actively engage Young Carers and their families in monitoring, reviewing and evaluating this strategy. A Stakeholder Group will also be established.

11. Appendices

Appendix 1 - Legal Framework

Disabled Persons (services, consultation and representation) Act 1986

The Children Act 1989

National Health Service and Community Care Act 1990

Carers (Recognition and Services) Act 1995

Human Rights Act 1998

Carers and Disabled Children's Act 2000

The Children Act 2004

Carers (Equal Opportunities) Act 2004

Guidance – Appendix 2

DFES circular 10/99 Social Inclusion: Pupil Support

National Service Framework for Mental Health 1999

Standard 6 - Caring for Carers

National Carers Strategy *Caring about Carers* DH 1999

The Framework for Assessment of Children in Need and their Families 2000

Young Carers Service Framework (Quality Protects 2003)

1. Every Child Matters 2004

National Service Framework for children, young people and maternity services DH/DfES 2004

Working Together to Safeguard Children, 2006

Putting People First 2007

2. National Carers Strategy: Carers at the heart of the 21st Century Families and Communities. HMGov 2008

Think Family: Improving the Life Chances of Families at Risk – DCSF 2008

Common Assessment Framework, ECM CWDC July 2009 updated

Your child, your schools, our future: building a 21st century schools system – DCSF 2009

UK Convention on Rights of the Child

Resources – Appendix 3

The Princess Royal Trust for Carers - www.youngcarers.net; www.youngcarers.org/professionals

The Children's Society Young Carers Initiative – www.youngcarer.com

The Whole Family Pathway 2008 – web-based tool

“Making it Work – good practice with young carers and their families” J Frank

Young Carers Research Group, Loughborough University – www.iboro.ac.uk/department/sscentres/YCRG/

Guidance for schools supporting Young Carers - 2009

www.healthyschools.gov.uk

Cornwall - Appendix 4

Cornwall Children and Young People's Plan 2008-11

Cornwall Carers Strategy 2010-13

Cornwall Young Carers Project

01209 614956

www.cornwallrcc.co.uk

Young Carers Pathfinder Project

DAAT 01872 354471