Supporting young carers

Wendy Nicholson
National Lead Nurse
Children, young people and families

Chief Nurse Directorate
Public Health England

March 2016
Young carers... your challenge

www.childrenssociety.org.uk
An absolutely electric energy' at the Young Carers Festival | The ...
Caring matters – the policy context

• **Recognised, valued and supported: next steps for the Carers strategy**
set out the priorities for carers and identifies the actions to ensure the best possible outcomes for carers and those they support, including:
  • supporting those with caring responsibilities to identify themselves as carers at an early stage,
  • recognising the value of their contribution
  • Involving them from the outset both in designing local care provision and in planning individual care packages enabling those with caring responsibilities to fulfil their educational and employment.
  • Potential personalised support both for carers and those they support, enabling them to have a family and community life supporting carers to remain mentally and physically well

• **Improving support for young carers: family-focused approaches**

• **Children and families Act** – access to carers assessment

• **NHS Commitment to carers** – NHS England working with NHS IQ

• **NHS England** – 5 year forward view
‘Defining carers’

What do we mean by carers?

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

- Anyone can become a carer; carers come from all walks of life, all cultures and can be of any age. Many feel they are doing what anyone else would in the same situation; looking after their mother, son, or best friend and just getting on with it.

What is a young carer?

Young carers are children and young people who often take on practical and/or emotional caring responsibilities that would normally be expected of an adult. Some take on inappropriate care. Young carers often take on practical and/or emotional caring responsibilities that would normally be expected of an adult. A young carer may do 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 with physiotherapy.
- Personal care, such as dressing, washing, helping with toileting needs.
- Administering medication.
- Looking after or “parenting” younger siblings.
- Emotional support.
- Interpreting
- Managing the family budget, collecting benefits and prescriptions.
The NHS Five Year Forward View

• The NHS Five Year Forward View was published in October 2014 and sets out a vision and a direction for the NHS looking ahead at least 5 years into the future.

The NHS is incredibly important for carers in several ways:

• How the NHS treats the person being cared for – the quality of that interaction, information and advice directly impacts on carers’ own health and well-being;

• How the NHS treats the carer as someone who puts their own time and knowledge into caring for someone who is a patient of the NHS and;

• How the NHS treats the carer in terms of their own health and well-being.

• As the “Forward View” rightly points out, health and well-being will need new partnerships with local communities, local authorities and local employers.
A spot light on young carers:

Killer Facts:

• Currently 5.8 million people (10% of the population in England & Wales) identify themselves as unpaid carers, caring for someone with an illness or disability.

• Over 1/3 of the population of England and Wales (37 per cent, 2.1 million) provide 20 or more hours of care a week.

• Since 2001, the number of people caring for 50 hours or more a week has increased by 270,000 - a 25% increase.

• The census demonstrated that the general health of carers deteriorates incrementally with increasing hours of care provided. People caring for 50 hours or more a week were more than twice as likely as those not providing care to report their general health as “not good”.

• 9% of the 166,363 young carers in England care for 50 hours a week or more

• 80% care for 1-19 hours per week; and 11% for 20 – 49 hours per week

• 22% of young people under 16 in the UK (2.6 million) live with a hazardous drinker

• In the UK, 335,000 children live with a drug dependent parent (BMC Public Health 2009)

• Young carers have significantly lower educational attainment at GCSE level, the equivalent of nine grades lower overall then their peers e.g. the difference between nine Bs and nine Cs (The Children’s Society, Hidden from View, 2012).
Defining a young carer

- Noisy, disruptive, unkempt
- Poor school absence and poor attainment
- Quiet
- Withdrawn
- Small friendship network
- Bullied and underweight
What does that mean – the reality?

I look after my mum – she’s got mental health issues, grandad has dementia and gran, she has difficulty with her breathing. My little sister gets scared – worried about being taken away.

Mum self ‘armed recently when I called 999 they sent a police car…. Thought she had a gun! We laughed but sometimes its hard – I wouldn’t change anything .. Except a bit of help…..

My dad……
I love my dad but sometimes its hard, he get scared and he hates his wheelchair.

We couldn’t go to the bonfire cos he gets spooked by the fireworks – I get teased about when we did go – best not to go again.
Mam has to work so I help out I love being with dad – mum cries a lot

I remember the day I become a carer – 2 days after my 7th birthday – I’m 19 now. Dad worked away a lot back then, so I started looking after mum and my brother – I got into trouble a lot but sorted my head out.

I didn’t want a label – I am me, a son, a boy

I am training to be a mental health nurse and I have a girl friend – I support my brother I don’t want him to get the same label.

Supporting young carers
I remember the day I became a young carer – it was my 7\textsuperscript{th} birthday, at 15 I didn’t feel right undressing and bathing my mum – it wasn’t dignified for her…. I knew we needed help.’

‘Just someone to ask \textit{me how I am} would mean so much…

‘I don’t have time for \textit{me} to be me or to find head space….

Why would I tell a teacher? I wanted confidence in confidentiality

‘I care because I \textit{can}……….’
The fragility of caring

The web of caring – complex and fragile

Supporting young carers
Why a focus from community nurses?

School nurses

• A universal service - all school-aged children have access to a school nurse – in and out of school

• Children and young people told us they trust their school nurse – they are easy to talk to and it’s confidential (BYC 2011)

District nurses and General Practice nurses:

• 1 in 4 of 75yr olds have input from a district nurse – rising to 1 in 2 of all over 85yrs olds

• More than 300 million GP consultations in 2008/9

Community nurses – supporting carers and families to navigate through health and social care services
School nurses leading public health delivery and universal support

- Re-affirming the leadership role of school nursing services in the delivery of public health to school-age children
- Holistic care and support both in and out of school settings
- Delivery centred around the child, young people and family
The delivery model for school nursing

An opportunity for school nurses to re-claim their role as leaders and delivers of public health to school aged children

Your Community describes a range of health services (including GP and community services) for children and young people and their families. Health visitor & School nurses will be involved in developing and providing these and making sure you know about them.

Universal Services from your school nurse team provides the Healthy Child Programme to ensure a healthy start for every child this includes promoting good health for example through education and health checks, protecting health eg by immunisations and identifying problems early.

Universal Plus provides a swift response from your school nurse service when you need specific expert help which might be identified through a health check or through providing accessible services where you can go with concerns. This could include managing long-term health issues and additional health needs, reassurance about a health worry, advice on sexual health, and support for emotional and mental health wellbeing.

Universal Partnership Plus delivers ongoing support by your school nursing team as part of a range of local services working together and with you/your family to deal with more complex problems over a longer period of time.
Support through universal services

4-5-6: Health visitors and school nurses leading the Healthy Child Programme

0–5 years
HEALTH VISITING

5–19 years
SCHOOL NURSING

0–19

Safeguarding

HCP
HEALTHY CHILD
PROGRAMME

ACCESS
EXPERIENCE
OUTCOMES

VISIBLE
ACCESSIBLE
CONFIDENTIAL

Someone I know and trust.....
Defining support – School nurses will…

Supporting the health and wellbeing of young carers

Understanding the role and challenges for young carers is essential. School nursing teams are well placed within schools and wider community settings to support young carers. The school nursing model provides a useful framework on which to plan and structure service delivery and tailored support. The model, as outlined in Getting it Right for Children, Young People and Families below outlines the contribution the school nursing team can provide to ensure young carers are supported through partnership and effective approaches.

Compassion in practice: Nursing, Midwifery and Care Staff: Our Vision and Strategy provides a platform to examine the core values of school nurses and their contribution to supporting young carers. The purpose of public health nursing is to maximise the contribution to high quality, compassionate care and to achieve excellent health outcomes. Values and behaviours are at the heart of all we do. Foundation to the implementation of this pathway is underpinned by six fundamental values listed below. Young Carers and professionals vision of these values are as follows:

**Care**
- Delivering the Healthy Child Programme 5-19, identifying and assessing young carers’ needs
- Contributing to the development of a crisis plan for children, young people and family
- Providing timely, tailored support (non-judgemental)
- Promoting positive health and wellbeing

**Compassion**
- Ensuring whole family approach
- Providing holistic support which reflects need and individual circumstances
- Showing respect and dignity
- Demonstrating strong desire to support identified health and wellbeing issues.
- Building trusting relationships which reflect empathy

**Competence**
- Acting as an expert in children and young people’s health
- Identifying issues early providing timely intervention
- Assessing young carers role and its impact
- Raising awareness of local services and referral to appropriate services
- Understanding and sharing best practice
- Empowering young carers, building on their strengths, resilience and competence

**Communication**
- Developing key partnerships and collaborating with:
  - Young carer
  - Peers and friends
  - Parents/family
  - Wider health services including community nursing and GPs
  - School
  - Voluntary services
  - Youth Offending Services
  - Adult services
  - Mental Health Services
  - Substance Misuse Services
- Ensuring clear lines of communication
- Ensuring offers of support are actualised and timely
- Ensuring services working in partnership using local assessment tools

**Courage**
- Knowing when to question/challenge
- Embracing innovation and new ways of working
- Acting as advocate and confidant
- Being tenacious, seeking solutions, and maintaining the commitment to improve support
- Working transparently with young carers and their families

**Commitment**
- Achieving optimum health and wellbeing for young carer
- Including young people in service developments and decisions where appropriate
- Engaging with young carers services and other health services (dentists, GPs)
- Improving delivery through sharing what works
- Ensuring services meet quality standards
- Ensuring mechanisms are in place to review and evaluate care plans
- Ensuring services meet You’re Welcome Quality Criteria and that young people are involved in service improvement
Messages from young carers for nurses

- Recognition that caring responsibilities can affect my health & wellbeing
- Services that are non-judgemental, who listen to me, understand and support needs
- Reassurance that school nurses have the skill, knowledge, training and confidence to support me
- Only have to tell their story once and not to feel pressured into sharing information
- To be able to contact my parent and for time out when things are difficult
- Access to support and respite when I need it most to avoid crisis
- Confidence that they have’ time to be ‘me’ but know that my caring responsibilities are being met
- To be recognised as an ‘expert’ in care & my contribution valued
- Non-intrusive support and tailored to my needs
- To be treated like other children and young people but remember I may have additional needs and need support
Seamless support & Making Every Contact Count

Ask me how I am

Carer

Identifying carers

Identifying health and wellbeing

Integrated support across the life course

Improved health and wellbeing for the carer & cared for

School nurses

District nurses

GPNs

Working with health, social care & Vol Sector

School nurses

District nurses

GPNs

The Healthy Child Programme 0-5: Pregnancy to the first five years

The Healthy Child Programme 5-19: A full range of interventions that commissioners and their families should consider to support children and young people;

The Healthy Child Programme 5-19: "Preparing for life"—"Ready for life"
Improving health and wellbeing outcomes

Supporting carers improves outcomes for the carer and the ‘cared for’ eg:

- Reducing hospital admissions
- Reducing re-admissions
- Improved patient experience
- Support for preferred place of death
- Carer quality of life
- Reduces isolation

In young carers:

- Positively affects attainment and attendance
- Healthy eating and dental health
- Emotional health and wellbeing
Nursing work stream to support carers

Young carers

Working with partners to support school nurses in championing the health & wellbeing of young carers:

- Partners: **young carers**, QNI, RCN, SAPHNA, Carers Trust, Children’s Society
- 6 cohorts of champion training – over 400 all pledged to make a difference – and are locally
- RCN e-learning: http://rcnlearning.org.uk/cms/young-carers/
- #weschoolnurse young carers chat
Supporting fulfilled lives – utilising expertise

• Carers are experts in ‘care’ and often feel undervalued
• Many carers – young carers feel isolated
• Many young carers find the transition to being an adult carer difficult and traumatic
• Many young carers – opt for ‘caring’ occupations – some young carers struggle to meet the education requirements or are not supported to apply themselves

Ask me how I am
A supportive network - Opens the world of opportunity
Together we can overcome challenges

Sometimes a problem or issue is too challenging or substantial to be overcome by just one person. Penguins have known this and demonstrate the most extraordinary teamwork to protect themselves from adversity.

This is an award for a team who has prevailed in the face of adversity.
Making a difference!
Let’s make every contact count… become young carer aware today

Thank you to:
Contact and useful resources

Wendy.nicholson@phe.gov.uk

@WendyJNicholson

School Nursing Vision:
http://dera.ioe.ac.uk/13952/1/dh_133012.pdf

School Nursing Pathways and Fact Sheets:

Experiences of a young carer:
https://vivbennett.blog.gov.uk/2014/03/31/young-carer/

Through health and high water: a young carers perspective:
https://publichealthmatters.blog.gov.uk/2014/08/06/through-health-and-high-water-a-young-carers-perspective/

Delivering the ambitions of living well for longer: A carer’s perspective:

Young Carers pathway: