Community Nursing

Supporting the health and wellbeing of carers across the life course

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‘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.
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
• (BMC Public Health 2009).
• 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).
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
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
Who cares?

Lizzie is 38yrs old and has a long history of mental health issues, admitted to A&E on Friday evening at 10pm after self harming – accompanied by Joe her next of kin and main carer. Joe was asked to remain in the waiting area whilst Lizzie was assessed. Lizzie was distressed and agitated.

Ellie has a full time occupation, she is the main carer for:
• a disabled sibling
• grandfather with dementia – her grandmother recently died, whom she also supported (COPD)

Zeeta is a full time carer for;
• 73yr old Hanir
• 42yr old Anwar
• 6yr old Jaz

Joe is 14yrs old and has been a carer since he was 8yrs old

Ellie is a scholar (school!), she is 13yrs old and has been a carer for 7yrs – since her sibling started school, she supports her grandparents whilst her mother works to support the household

Zeeta is a grandmother, wife, mother & a carer for 16yrs since her husband suffered a fall, subsequently her 42yr old son’s epilepsy become less controlled. Zeeta’s grandson was born with cerebral palsy and she carers him to supported her daughter’s return to work,

See who I am, Break through the surface. Reach for my hand
Listening to carers

‘I am a young person first but I just have extra responsibilities – caring!…….’

I remember the day I became a young carer – it was my 7th 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 me how I am would mean so much…

I am not a carer … I am a husband who cares for his wife..’

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

‘going to work… it offers me the respite and normality I need.’

‘the threshold for respite is so narrow… impossible to get any help unless you can’t do anything for yourself. Yet you to carry on caring even when you are breaking point.’

‘when some-one asks you what you do and you say you are a full time carer … they judge your worth and make assumptions…

‘I care because I can…….’
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

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
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
- 3 cohorts of champion training – over 150 all pledged to make a difference – and are locally
- #weschoolnurse young carers chat
Nursing work stream to support carers

Adult carers

- Working with district nurses and practice nurses in supporting and championing the health and wellbeing of adult carers
- 1\textsuperscript{st} cohort of champions
- New pathway: 
- QNI E-learning: 
  http://qni.org.uk/for_nurses/supporting_carers
- LJMU review of evidence
- Further training and awareness raising: 
  http://qni.org.uk/events/195
  http://qni.org.uk/events/194
Messages from carers for nurses

**Adult carers**

- We want to keep a normal home routine
- Take time to speak to our families and carers to find out our needs
- Help us with our ‘wellbeing’ and mental health
- Help us to stay in our home with as much support as is necessary
- Tell us what carer breaks and respite are available to us
- Help us to identify triggers to anticipate and prevent crises
- Help us to get support to manage care alongside paid employment/childcare responsibilities
- Recognise increasing frailty of older carers/likelihood of spouses undertaking mutual caring roles
- Support young carers with their transition role to adult carer

**Young carers**

- 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

Identifying carers
Identifying health and wellbeing
Integrated support across the life course

School nurses → District nurses → GPNs

Improved health and wellbeing for the carer & cared for

Working with health, social care & Vol Sector

Ask me how I am
Supporting fulfilled lives – utilising expertise

• Carers are experts in ‘care’ and often feel undervalued
• Many carers – young and adult feel isolated
• Many young carers find the transition to being an adult carer difficult and traumatic
• Many carers adult carers see work as ‘respite’ and an opportunity to normalise their life
• Many carers – young and adult 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
Dare to care - making a difference!

Will you join me and those nurse champions who have already committed to make a difference for carers?

Let’s make every contact count… become carer aware today

Thank you!
Contact and useful resources
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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:

District Nursing Vision:

District Nursing visual:

Adult carers pathway:

QNI carers on-line training:
http://qni.org.uk/for_nurses/supporting_carers