

What next for Carers?

Summary Report

On 1st May 2014, Healthwatch Nottinghamshire hosted the county's first Carers Conference on behalf of Nottinghamshire County Council and the local NHS Clinical Commissioning Groups.

Over 145 local carers and professionals attended the event at the Summit Centre, Kirkby-in-Ashfield.

Carers...the Facts

5.4 million

Carers in England, including

166,363

Young carers under 18

66%

Of carers report health problems related to caring

£119 billion

The amount unpaid carers save the UK economy every year

49%

Of carers are struggling financially because of their role

Highlights from...the Speakers

The first session of the conference saw four speakers give their perspective on carers and caring, from both a local and national angle. It was clear that they all had the same message...**GET INVOLVED!**

"You as a carer can make a difference. See the professionals and local government as allies, and if you don't like things, change them together"

Dame Philippa Russell (Chair of the Standing Commission on Carers)

"Whatever we say we do that's good, there's always a thousand things that we can learn from in terms of doing things better"

David Pearson (President of ADASS)

"Don't stand outside the window shouting in through it, go into the meeting, tell them your problems, tell them what needs to be changed"

Jim Radburn (Founder of Carers in Hucknall)

"Get the support—it might come from professionals, it might come from friends, it might come from voluntary sector organisations...We are not very good at accepting help, but once you accept it then it does make life much easier"

Diane Davies (Local Carer)

To see videos of all the talks please visit the Healthwatch Nottinghamshire website at www.healthwatchnottinghamshire.co.uk/carersconference

Highlights from...the Workshops

Carers and...the Care Bill

Jane North, Programme Manager for Nottinghamshire County Council, led a workshop on the Care Bill. She provided information on the main changes that this Bill will bring, such as:

- * The requirement for all Local Authorities to provide comprehensive information and advice about a range of services
- * Changes to the way people pay for or contribute towards their support, including a cap on care costs at £72,000
- * Carers given equality in law with those they care for — ALL carers will be entitled to a needs assessment
- * A legal responsibility to ensure smooth transition for people with care needs to adulthood

The main issues identified by this workshop were:

- The **£72,000 figure of the 'cap' is misleading** — this does not include 'hotel costs' such as the room itself, food and heating
- There were concerns about **carers getting the information** about these changes, especially if GPs don't have leaflets or other resources available
- There is **difficulty in interpreting the Care Bill** until it becomes a Care Act and guidance is available — carers present requested a session on the guidance when it comes out.

Carers and...Benefits

Bev Pearson, Partnership Manager for the Department for Work and Pensions (DWP) led a workshop on carers and benefits. She provided the latest information on how to claim Personal Independence Payment (PIP), Attendance Allowance, and Carers Allowance, and how it all works

The main issues identified by this workshop were:

- **Overlaps between Carers Allowance and other benefits**, particularly the fact that carers allowance is not paid to individuals who claim a state pension
- Carers Allowance totals **just 37p per hour** for those who provide 24/7 care
- People **with learning disabilities have difficulty claiming benefits**, both in receiving enough support and with having evidence of their condition due to lack of yearly health reviews being offered.



Workshops in progress



Carers and...Health

Jane Kingswood, Community and Partnerships Worker for Healthwatch Nottinghamshire, led a workshop on Carers' Health to get people thinking about how services could work better for carers.

The key themes to come out of this workshop were:

- There is a **need for a one stop shop for information** — one phone number, so there is no confusion about who to contact. This needs to be available before carers get to crisis point
- Services, especially **GPs need to be flexible around carers' needs**, particularly regarding appointment times and information requirements
- It shouldn't be left to carers to coordinate everything—they need **more support** in ensuring continuity of care
- Services need to be more **consistent**, both across postcodes and in the quality offered
- More support is needed when the caring role comes to an end



Many of us
don't know
where to go
for information
and advice

Carers and...Personal Health Budgets

Morwenna Foden, Commissioning Manager at NHS Bassetlaw CCG led a workshop on Personal Health Budgets.

A Personal Health Budget is an amount of money that is allocated to a patient. The patient has choice and control over how this money is spent to meet their own health and wellbeing outcomes.

Personal Health Budgets are only just starting to roll out within the NHS; patients eligible for Continuing Healthcare have the 'right to ask' from April 2014, the 'right to have' from October 2014.

The workshop group were very positive about the roll out of Personal Health Budgets, but identified that:

- Individuals' support **plans must be detailed and up-to-date**, and adequate time spent carefully conducting reviews
- **We must be open minded** to requests and 'think outside the box' about what will improve wellbeing

Carers and...the County Council Carers Strategy

Penny Spice, Commissioning Manager for Nottinghamshire County Council led a workshop to gather views on the new County Council Carers Strategy.

The attendees of this workshop had a lot to say about what advice and support carers need, including:

- One stop shops for information, or packs of carers information available
- More leaflets available for those who don't have internet access
- Regular reviews of information so that it doesn't go out of date
- More work with the local media
- Parity from the start
- More professional training available for carers—especially around dementia

Highlights from...Question Time Panel

In the afternoon session of the event, we invited our audience to submit questions to our 'Question Time' panel:

Jon Wilson (Deputy Director, Adult Social Care, Health and Public Protection, Nottinghamshire County Council)

Rob Gardiner (Deputy Chief Executive, Carers Federation)

Jim Radburn (Founder, Carers in Hucknall)

Dame Philippa Russell (Chair of the Standing Commission on Carers)

Elaine Moss (Chief Nurse and Director of Quality, Newark & Sherwood CCG and Mansfield & Ashfield CCG)

The panel was chaired by **Claire Grainger**, Chief Executive, Healthwatch Nottinghamshire.

Your Questions...

15 questions were submitted in total, and we had time to put 7 of these to the panel on the day.

1. Will the new Care Bill affect the respite care that carers currently receive?
2. Can we have a one stop shop for information and advice?
3. What is the 'Golden Number' We don't know about it!
4. How will carers get to find out how the Care Bill then Care Act will be implemented locally?
5. As individuals are encouraged to self-manage their condition, there will be less paperwork to use as evidence for DWP to assess benefit rights. How can we create systems that assist the carer/patient to make a claim?
6. I coordinate a volunteer care group but we are being underused and at risk of losing volunteers. How can we increase the number of calls we are getting?
7. How can we improve care planning when people are discharged from hospital?

You can view the answers that were given by panel members in full by visiting:

www.healthwatchnottinghamshire.co.uk/carersconference

Or request a copy by phoning **0115 963 5179**

The panel also committed to providing a response to those questions not asked and these responses will be made available.

Spotlight on...Question 1

John Wilson informed us that the Care Bill/Act does not remove any eligibility for **respite care**. Access to the care is coordinated through the County Council, so if you're in need of a break from caring, just call the 'Golden Number' to find out more about respite care.

Spotlight on...Question 3

The golden number is the phone number for the Nottinghamshire County Council Customer Service Centre.

This is a really useful starting point for information on social care services, and particularly for carers' services and assessments.

The Golden Number is 0300 500 80 80.



The Question Time panel in action

Key Themes...

The Question Time Panel created some interesting debate on a range of issues. Key themes were:

GPs

- Named GPs are essential
- GPs need Carers Leads — evidence suggests this is very effective. Knowledge of this scheme needs to be improved.
- Yearly health checks/reviews
- Information about support groups/services doesn't seem to happen through GPs

This exact discussion has been going on for 30 years...please can we have a little more speed?

Local Carer, on hospital discharge

Involvement

- Timing of consultation events need to suit carers, 9am or 10am starts are difficult
- Access to PPG (Patient Participation Groups) at GP surgeries is variable — some are still online.
- There is a need to ensure BME (Black & Minority Ethnic) and other 'hidden' communities are included—people who don't feel like they are represented anyway, even before they are a carer.
- Current low take up in support groups

There are two commitments from myself and health colleagues - firstly CCGs will ensure information is sent on contact details, and secondly this will be fed into our Primary Care Strategies

Elaine Moss,
Newark & Sherwood/Mansfield & Ashfield CCG

We often think we are providing lots of information. Clearly this is not getting to everyone when they need it

Jon Wilson,
Nottinghamshire County Council

Integration

- We need to make sure carers' services are linked across all pathways
- Too many people involved in hospital discharge—better planning is needed and community services need to play a bigger role in keeping people out of hospital
- Can we have an information service that spans the city and county?

As a carer our second home is the GP...this is a very obvious place where the information needs to be

Local Carer

Access to Support & Services

- How does one access respite care?
- Lack of services for ASD (Autistic Spectrum Disorder) children
- 7 day services are needed
- Difficulty knowing which social care agency to choose as the County Council can't comment on care quality

Access to Information & Advice

"We need a one stop shop", however:

- Clinicians must be involved in its setup
- There must be consistency over point of access
- It may need to go further than information, e.g. provision of carers passports

What Next...?

Although we had a very useful and informative day at the Carers Conference, as the day ended it was clear that everyone was eager to ensure that the feedback gained would be acted upon and lead to **real improvements for carers**. We asked local service providers what they were planning as a result of the conference. Here is what they have told us so far:

Nottinghamshire County Council have told us that...

New and Improved Services...

- * The Carers Support Service team based at the Customer Service Centre is growing - **2** full time members of staff are joining the team this summer. The workers will give support and advice over the phone, completing carers assessments and signposting carers to places of support.
- * Carers in Bassetlaw will soon be able to access **short breaks via a direct payment**, allowing for more flexibility, choice and control for carers.
- * **Compass workers** (former carers of people with dementia) will work across the county providing specialist advice and support to carers supporting people with dementia
- * A **new 'End of Life' service** is being launched and will support carers of people who are nearing the end of their life
- * A network of home based care providers will provide **support to carers in crisis** from September 2014
- * **Awareness raising within the organisation** is taking place by reviewing staff guidance and procedures. Alongside this process the County Council communication team will help to keep carers at the forefront of social care staff minds as they introduce new and improved processes.

Further Events...

- * A series of **carer-led events** is being planned. Following a successful programme of events in Nottingham City, The Carers Forum and Independent Voices for Engagement are developing plans for 8 county wide events to support carers looking for advice and support.
- * Work will continue with health colleagues to **raise awareness of carers through GP surgeries** and joint working through events. A young carers' week is being planned in 2014 to help identify and raise awareness of the needs of young people across the County providing care.



Workshops in progress on the day

Improved accessibility of information...

- * A **Carers' Information pack** is being developed with Clinical Commissioning Groups and carer groups. This pack (available online and offline) will create a pathway for carers and give a comprehensive view of services offered by all local health and social care organisations.
- * A **carers' newsletter** is being developed to keep carers in the loop with news, information and advice.
- * A **single contact database** to capture information about individuals and organisations interested in the carers agenda has been created - if you want to be included email julian.wing@nottscg.gov.uk
- * Carers will be able to **access information online and offline** through the Council website, facebook and twitter pages - these will complement road shows, events and new paper based information being developed.



Browsing the information stands at the event



NUH Carers Card

Nottingham University Hospitals NHS Trust (NUH) have told us that...

- * Action following the Carers Conference will be to promote information and support services through the distribution of NUH Caring for Carers Cards and promoting this information on information screens throughout the Trust.

In our role as an independent organisation helping local people get the best out of their local health and social care services, Healthwatch Nottinghamshire will....

- * Continue to encourage carers to give feedback about services they use across the county
- * Use this feedback to influence the ongoing development of carer's services, particularly focussing on encouraging integration of services where possible
- * Contribute to ongoing work on improving access to information for carers



Healthwatch volunteer on the registration desk

Feedback from carers has contributed to all of these actions being taken.

We hope that carers will continue to give feedback and get involved in the services they use, so that many more improvements can be made in the coming weeks, months, and years!

This summary report was produced by Healthwatch Nottinghamshire.



Healthwatch Nottinghamshire is an independent organisation that helps people get the best from their local health and social care services.

Go to **www.healthwatchnottinghamshire.co.uk/carersconference** to view the full resources from the Carers Conference, including videos of the speakers, presentation slides, workshop notes, and a detailed write-up of the Question Time session, or call our office to request printed copies of the resources you require.

