



## **Health Scrutiny Committee:**

### **Review of Carer Support Services**

#### **September 2018**

### **Background**

- 1.1 During 2015 the Health Scrutiny Committee carried out a review of end of life and palliative care services. As part of the evidence gathering for that review councillors spoke to carers about both the end of life care received and the support that they received as carers of someone at the end of their life. The carers spoken to commented that they felt that the experience of being a carer of a person receiving end of life care could be lonely and isolating. They felt that their caring responsibilities took over their life for that period and they also discussed that there was a feeling of being inadequate to carry out the role. While recognising that these were small scale anecdotal examples, in its report the Committee highlighted the need to recognise the potential for social isolation of carers and consider how providers can support carers. The Committee also wanted to ensure that there were appropriate mechanisms for ensuring carers are aware of the support available to them and how to access it. These recommendations were fed into the strategic review of support for carers carried out by Nottingham City Council and Nottingham City Clinical Commissioning Group in 2016.
- 1.2 Following this review, carer support services were jointly commissioned by Nottingham City Council and Nottingham City Clinical Commissioning Group and new services commenced on 1 April 2017.
- 1.3 The Health Scrutiny Committee decided to explore whether the newly commissioned carer support services were meeting the needs of carers in the City and held an initial evidence gathering session with commissioners and provider organisations in January 2018. Then, during summer 2018, the Committee established a study group to review how service user feedback is used to inform the commissioning and provision of carer support services to ensure that services meet the needs of carers.
- 1.4 The members of the study group were:
  - Councillor Merlita Bryan
  - Councillor Ginny Klein
  - Councillor Anne Peach (Health Scrutiny Committee Chair)
  - Councillor Adele Williams
  - Councillor Cate Woodward

### **Evidence gathering**

- 2.1 The study group based its findings and recommendations on:
  - Desk-top research
  - Evidence previously gathered by the Health Scrutiny Committee
  - Speaking with adult carers and young carers at an event held at The Council House as part of Carers Week

- Contributions from commissioning organisations
  - Lisa Lopez, Commissioning Manager, Nottingham City Council
  - Ann Ashworth, Contracts Officer, Nottingham City Council
  - Reeve Palmer, Commissioning Officer, Nottingham City Clinical Commissioning Group
- Contributions from provider organisations
  - Ray Gardiner, Carers Federation
  - Kevin Ray, Carers Trust

2.2 The Committee would like to thank all of those who contributed to this review. All contributions were very much appreciated.

2.3 Notes from the evidence gathering sessions are held by the Senior Governance Officer who supported the review, contact details for which can be found at the end of the report.

## Context

### 3. National context

3.1 The 2011 Census<sup>1</sup> identified that 5.4million people in England were providing unpaid care, with over a third of carers providing 20 or more hours of care per week. This is likely to be a significant under-estimation because many carers don't self-identify themselves as such. In addition, demand for health and social care support is expected to rise in future years so the number of carers is likely to increase in line with that.

3.2 Carers account for approximately one in ten of the population and are more likely to be female than male. The Census showed that the proportion of carers amongst Black, Asian and Minority Ethnic (BAME) communities is approximately equivalent to that of the general population although there is a higher than average proportion of carers and more hours of unpaid care provided in some communities – Black Caribbean, Indian, Pakistani and Bangladeshi communities. Familial and cultural expectations in some communities mean that caring is seen as a normal role for a family so carers may not self-identify and therefore not access any support.

3.3 The Nottingham City Joint Strategic Needs Assessment Chapter on Carers<sup>2</sup> states that carers typically experience higher levels of stress and poverty and poorer physical and mental health than the general population due to the demands of their caring role. The 2011 Census showed that the general health of carers deteriorates incrementally with the increasing hours of care provided. 5.2% of carers reported that their own health was 'not good' and this increased to almost 16% amongst those caring for more than 50 hours per week. Only 12.1% of female adult carers and 9.3% of male adult carers were working full time alongside caring responsibilities.

3.4 Young carers can experience difficulties in school, feelings of loneliness and isolation and report feeling stigmatised by teachers and by their peers. Young carers have significantly lower educational attainment at GCSE level and are more likely than the national average to be not in education, employment or training

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<sup>1</sup> Cited in Nottingham City Joint Strategic Needs Assessment (2017) Carers

<sup>2</sup> Nottingham City Joint Strategic Needs Assessment (2017) Carers

(NEET) between the ages of 16 and 19 years<sup>3</sup>.

3.5 The Carers UK annual State of Caring survey<sup>4</sup> found that half of unpaid carers said that they expected their quality of life to get worse in the next 12 months.

3.6 Local authorities have a statutory duty to proactively identify, assess and support carers in their area under the Care Act 2014<sup>5</sup>. The Care Act defines a carer as anyone who provides any amount of unpaid care. Local authorities have to identify carers' needs through the completion of statutory Carers Assessments, and there is a duty to carry out assessments for all carers who ask for one and to pro-actively identify and offer assessments to other carers. Once the assessment is completed the local authority must decide whether the carer's needs are eligible for support from the local authority.

3.7 Under the Children and Families Act 2014<sup>6</sup> local authorities must offer an assessment where it appears that a child is involved in providing care. The authority must consider whether the care being provided by the child is excessive or inappropriate, and how the child's caring responsibilities affect their wellbeing, education and development.

#### **4. Local context**

4.1 The 2011 Census<sup>7</sup> found that there were approximately 27,000 carers in Nottingham City which is approximately 8.8% of the total population. This is a slightly lower percentage than England (10.2%) and East Midlands (10.8%). This is likely to be an under-estimation of the actual number of carers because many carers do not self-identify themselves as such. Approximately 3,300 of these carers is aged under 25 years old, 2.5% of which are under 16 years old. Again, this is likely to be an under-estimation because, for a range of reasons, many young carers are currently not identified. In addition to the reasons why carers often don't self-identify as such, many young carers don't identify and access services for reasons including family loyalty, stigma, bullying, lack of awareness of entitlements and a reluctance to seek formal help<sup>8</sup>. 20% of carers aged under 16 years provide over 20 hours of care per week.

4.2 The proportion of women to men providing care is approximately the same for Nottingham, East Midlands and England, with 7.98% of men and 10.4% of women in Nottingham providing some amount of care.

### **Key findings**

5.1 Following the strategic review of support for carers carried out in 2016, Nottingham City Council and Nottingham City Clinical Commissioning Group jointly commissioned new carer support services which commenced on 1 April 2017.

5.2 Carers Trust East Midlands is commissioned to provide a Carers Hub which provides a single point of contact and a range of services including:

- providing information, advice and guidance

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<sup>3</sup> The Children's Society (2013) Hidden from View: The experiences of young carers in England

<sup>4</sup> Carers UK (2018) State of Caring

<sup>5</sup> The Care Act (2014) HM Government

<sup>6</sup> The Children and Families Act (2014) HM Government

<sup>7</sup> Cited in Nottingham City Joint Strategic Needs Assessment (2017) Carers

<sup>8</sup> Nottingham City Joint Strategic Needs Assessment (2017) Carers

- carrying out Carers Assessments as per the Care Act 2014, including outreach work to identify and support carers who haven't previously accessed support
- development of support plans when required following Carers Assessments
- ensuring support is available should an emergency occur involving the carer or cared for person
- providing group support sessions, drop in sessions and telephone support
- providing training for carers and signposting to training offered by other providers
- collating information on resources available to support carers

5.3 Carers Trust East Midlands also provides the Carers Respite service which provides time-limited, home-based respite care for carers of citizens who don't get respite through adult social care. It can be used for planned events such as attending medical appointments, hobbies and recreation activities, significant events such as weddings etc. Respite care is also available in an emergency for example when the carer is admitted to hospital or there is a family crisis.

5.4 Action for Young Carers is provided by Carers Federation to support young carers through a range of services including:

- providing information, advice and support across health, social care and schools
- carrying out Young Carer Assessments
- group based support and activities for young carers
- Young Carers app
- Ensuring support is available should an emergency occur involving the carer or cared for person
- Providing training for professionals on identifying young carers and the impact of being a young carer and signposting to training offered by other providers

Action for Young Carers works with the Carers Hub to develop support for young adult carers.

#### Contract monitoring and management

5.5 The services were commissioned to provide the following expected outcomes:

- improved carers' quality of life;
- increased identification and recognition of carers;
- improved physical and emotional wellbeing for carers;
- carers feeling more resilient and better able to continue in their caring role;
- reduced inappropriate caring roles and the impact of caring on young carers
- better/ more joined up personalised support for both the carer and the cared-for person; and
- carers able to fulfil their educational and employment potential, and to have a family and community life.

5.6 Nottingham City Council Contracts Management Team monitors and manages performance of provider organisations against the carer support contracts. Providers report on performance indicators, including number of people contacted, completion of support plans, carer satisfaction etc and this data is broken down by Protected Characteristics and also by the reason that the cared for person is being cared for and what the carer's role is with the cared for person. Providers are also required to submit narrative reports outlining progress and any issues.

- 5.7 The Contracts Management Team also undertakes visits to the services and gets feedback directly from carers. Quarterly review meetings are held to identify and discuss any issues.
- 5.8 In addition, there are national reporting requirements in relation to Carers Assessments.
- 5.9 Since the contracts commenced on 1 April 2017 there had been an increase in the number of statutory Carers Assessments that have been carried out compared with the previous year. All carers assessed had support plans developed and in the process of being implemented. Over 20% of all carers contacted, assessed and supported were from BAME communities which was in line with targets set.
- 5.10 Commissioners reported that they were currently satisfied with the carer support services that are being delivered by provider organisations, and provider organisations stated that they were pleased with how the contracts were going.

#### Information about support services available and identification of carers

- 5.11 The consultation carried out to inform the strategic review of support for carers in 2016 found that information on the support available for carers was not widely known about. This accorded with the anecdotal evidence received by the Health Scrutiny Committee as part of its review of end of life and palliative care services. Therefore this was an issue that commissioners wanted to address in the commissioning of new services.
- 5.12 Information about the provision of carer support services is available from a range of different sources, and the carers spoken to who had accessed services more recently cited a number of different ways that they found out about the support available to them including the Carers Hub, Action for Young Carers, LION, referrals from social workers, GPs. Commissioners felt that this suggested that the provision of information has improved. In addition the Carers Hub provides a single point of contact across Council and Clinical Commissioning Group and across City and County.
- 5.3 One of the challenges is that carers often remain 'hidden' from services and don't access support. Lots of people don't self-identify themselves as carers or don't access help until they have been carers for a significant length of time and may have had negative experiences. Therefore outreach and promotion is needed to increase understanding of what being a carer is and where to go to for support. For those carers who do not wish to access services, it is important that they are still aware of what support is available if their circumstances change. The JSNA<sup>9</sup> highlights that this could be particularly useful for some members of BAME communities who may not wish to utilise services as they may prefer to draw on family support networks in the first instance.
- 5.4 Therefore it could be useful to promote the availability of carer support services and how to access support more widely to the general population, rather than target specific locations/ methods of communication that those who have already self-identified as a carer would proactively look. This could include the provision of locally-specific information in ward newsletters and local authority publications such as The Arrow which goes to all households.

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<sup>9</sup> Nottingham City Joint Strategic Needs Assessment (2017) Carers

- 5.5 Some of the carers spoken to commented on the bureaucratic nature of accessing support both for themselves and for the cared for person. Both commissioners and providers acknowledged that the statutory Carers Assessment process is lengthy and bureaucratic and can dissuade carers from completing it. Therefore, in common with the nationally agreed approach, a lighter touch version is used locally. The Carers Trust representative provided assurance that the assessments carried out are only light touch in the sense that they don't go through the irrelevant questions, but relevant questions are discussed in detail and assessments typically take up to 1 hour.
- 5.6 Carers also gave feedback that it can be frustrating for carers when they are required to fill in forms requesting the same information multiple times e.g. about care packages and from carer support services. There are challenges in sharing information provided during assessments due to data protection restrictions but there could be scope to explore ways of enabling information to be shared to reduce the administrative burden on carers. This could also potentially improve services by making sure that relevant information is shared, for example providing information about carers to inform homecare assessments.

#### Support services provided

- 5.7 The carers spoken to value the support available to them for a variety of different reasons including that it takes pressure off of them; provides someone to talk to who understands their situation; night-sitters make things easier because carers don't have to get up in the night. Carers also commented that it can be helpful for a third party to explain to the cared for person that there is an impact of their caring responsibilities on the carer and this can result in the cared for person being more willing to accept help.
- 5.8 Carers spoke about the risks of social isolation and loneliness. In particular, young carers spoke about the need to have time for themselves to pursue other interests and the importance of having friends who understand to reduce risks of loneliness.
- 5.9 Services commissioned to support young people to have time for themselves and pursue outside interests includes a mix of group and individual sessions. The Carers Federation representative reported that the provision of activities is more difficult than previously because it is no longer included in the contract and has to be funded through external sources of funding. In addition, commissioners reported that they had feedback that some activities previously provided by the voluntary and community sector are no longer available due to funding pressures. Work is taking place within Nottingham City Council to explore what opportunities the local authority could provide young carers with free/ low cost access to e.g. leisure centres, in a similar way as happens for children being looked after. This work could be expanded to look for other potential sources of funding. Young carers commented positively on the Young Carers App.
- 5.10 While providers provide some support directly they also work through signposting carers to other sources of information and advice. For example some carers spoken to commented on needing support in getting Blue Badges and dealing with Direct Payments. Direct Payments is a complex area that requires specialist knowledge and therefore Carers Trust signpost and refer to the appropriate service rather than training staff to provide advice and support themselves.
- 5.11 Carers Trust also signpost carers to other providers that provide training on dealing with practical matters such as preventing and coping with falls. The

organisation does provide its own learning and development for carer support workers on issues such as infection control and medicines management and it does offer this training to carers alongside carer support workers. It would be useful if the Trust could also provide training on issues such as falls and handling directly to carers on the same basis.

- 5.12 Some carers commented on access to transport and the risk that a lack of transport options could contribute to loneliness by carers. Commissioners confirmed that transport is not available for any services due to financial pressures and the availability of a comprehensive public transport network in the City, but this hasn't been a recent change. They also confirmed that there is currently no funding available to introduce transport provision. However wider work is taking place within the local authority on reducing loneliness and there could be scope to incorporate carer issues into this work.

#### Timely provision of support services

- 5.13 Support sessions for adult carers are currently held in the morning in Clifton and Hyson Green and in the afternoon in Bulwell. There was feedback from some carers spoken to about a lack of support provision in the evenings, which would be useful for carers who are employed. Currently there are no sessions in the evening. Previously, the Carers Trust had held evening drop-in sessions in conjunction with Parkinsons UK but not many carers attended so the sessions were discontinued. However, the evidence provided by carers as part of this review indicates that there is a demand for evening sessions and Carers Trust is willing to explore the extent of this demand and how it could be met.

#### Respite care

- 5.14 Carers can access up to 100 hours of respite care per year through the Carers Hub. However it is not intended to be a long term solution or a substitute for a care package. The use of respite care is monitored and if carers are using it a lot then it may indicate that there is an inappropriate care package in place and carers are signposted to homecare for (re)assessment. However the contract does have some flexibility to provide additional respite hours in crisis situations.
- 5.15 Some of the carers spoken to reported that they felt that they couldn't use respite care because they couldn't leave the cared for person. Councillors heard that this can be a difficult situation and that Carers Trust tries to work with those individuals to address any issues. There are issues around trust and there was some feedback from carers that they had used respite care in the past and it wasn't successful, but Carers Trust believe that the issues often relate to care packages rather than the respite service. There was also some feedback from carers about homecare services which suggested a variable experience of care packages. However given the lack of clarity about the feedback, councillors requested additional information on service user feedback regarding the respite service specifically. This issue will be revisited by the study group at its next meeting.

#### Counselling

- 5.16 The Carers Hub contract that commenced on 1 April 2017 included a counselling service for adult carers. The uptake of counselling sessions was significantly less than initially expected and since the introduction of mindfulness activities the uptake of counselling had been very low. Therefore as part of savings to the Better Care Fund, funding for 1-2-1 counselling sessions was removed from 1 April 2018. The Carers Trust still provides mindfulness and wellbeing sessions as a preventative service to reduce the need for counselling. However, in providing evidence to the review, the Carers Federation representative suggested that there

was a gap around counselling services for carers. Councillors were informed that Carers Federation receives a lot of self-referrals from adult carers for counselling and that there is a steady demand from young carers for counselling due to their caring responsibilities or for issues that are compounded by their caring responsibilities. The organisation delivers some counselling for young carers but it is not funded as part of the contract. There is an additional challenge due to changes in British Association for Counselling and Psychotherapy accreditation which means that it is harder to recruit counsellors.

5.17 Commissioners maintained that their evidence of need was that there are some young carers who need counselling but it is very small (single figure) numbers and, as evidenced by the commissioning review, the demand for counselling by adult carers is also low.

5.18 Councillors felt that this conflicting information warranted further investigation and requested the provision of additional information on the level of need for counselling services. This issue will be revisited by the study group at its next meeting.

#### Engagement and support from partner organisations

5.19 The JSNA<sup>10</sup> noted that engagement with carers and carer support services is variable across healthcare providers, GP practices, care providers and schools but that these organisations have an important role to play in identifying, signposting and support carers.

5.20 Young carers spoken to raised the importance of support from schools and colleges, for example having the ability for the young person to contact home when needed, reduced homework pressure, awareness of bullying due to the reason for their caring responsibility. The JSNA<sup>11</sup> also found evidence that some young carers felt that their requests to school for additional time and flexibility were not taken seriously. Evidence from young carers, Carers Federation and the JSNA is that there is variable engagement by schools on carer issues. Some teachers are very understanding but others less so.

5.21 The Carers Federation works with schools, and carer support services are currently embedded in 12 out of 18 secondary schools in the City. There are staff champions in place and 30 young people have trained as 'carer champions' to support their peers. There has been good feedback on work taking place and this is being used to roll out models of good practice. This work should support young people in self-identifying/ being identified as a carer at an early stage.

5.22 Carers Federation reported that it can be more challenging to engage primary schools because they sometimes think that primary school aged children are too young to have caring responsibilities and therefore the information isn't relevant to them. There is a need to identify ways of engaging primary schools with this agenda.

5.23 Not all young carers want the support, help and advice of services. This can be for a variety of reasons including concern that if they are seen to need to ask for help then social workers could remove the young person from their home. Where possible young carers not engaging with support services are tracked and always have the option of engaging with services in the future.

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<sup>10</sup> Nottingham City Joint Strategic Needs Assessment (2017) Carers

<sup>11</sup> Nottingham City Joint Strategic Needs Assessment (2017) Carers



5.24 GP practices can often be the first place that carers present and therefore it is important that GPs and other healthcare professionals are aware of carer issues, the support that is available and where to signpost to. As part of their contract Carers Trust are required to work with GP practices. However, evidence from the Carers Federation was that there is a gap around young carer health issues, for example making sure that appropriate questions are asked when children and young people accompany adults to appointments. While there is an agreement to have GP Protected Learning Time on young carer issues, this is limited. Therefore there could be opportunity for Carers Trust and Carers Federation to work more closely together and co-ordinate their engagement with GP practices on young and adult carer issues.

5.25 When their contract commenced in April 2017 the Carers Trust worked closely with Nottingham University Hospitals NHS Trust at Queens Medical Centre to provide information about carer support services and engage with discharge teams. A drop in session is held every month which the Carers Trust reported to be going well and has resulted in a significant number of referrals for Carer Assessments. Carers Trust is looking at developing a similar session based on the City Hospital campus.

5.26 Some carers reported that they had difficulties in accessing mental health services for their cared for person and commented on the negative impact that this has on them as carers. The JSNA<sup>12</sup> states that nationally approximately 13% of carers care for someone with a mental health condition and this can present particular challenges for the carer. Mental health conditions can fluctuate, are often misunderstood and can cause considerable emotional distress to carers. Carers can sometimes also be reluctant to discuss their role due to stigma attached to mental health. The 2018 Carers UK survey found that carers want the NHS to be better at recognising and valuing the knowledge that carers have. Access to mental health issues and the impact on carers is a wider issue and therefore not within the scope of this review but could be an issue that the Health Scrutiny Committee wants to explore as part of its wider work programme.

5.27 Given that the cared for person can often also receive considerable support from homecare services, it is important that homecare workers are also aware of carer support services and what support is available to carers so that they could signpost to support as appropriate.

## Conclusions

6.1 It was clear that commissioners and providers are committed to ensuring all carers are appropriately supported in their caring role.

6.2 Overall councillors were satisfied with the current provision of carer support services but, based on evidence provided by carers, commissioners and providers, identified some opportunities for improvement. Recommendations for improvement are set out below.

6.3 Councillors were also satisfied with the processes in place to ensure that commissioners and providers receive service user feedback and use that feedback to improve services. The following recommendations have all been

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<sup>12</sup> Nottingham City Joint Strategic Needs Assessment (2017) Carers

discussed with commissioners and providers and met with a positive response and enthusiasm for ensuring that services meet the needs of users.

- 6.4 It is intended that progress on the areas identified for improvement will be reviewed by the study group in December 2018 and reported to the Health Scrutiny Committee in January 2019.
- 6.5 In addition, councillors requested additional information in relation to respite services and the need for counselling services. This evidence will be reviewed in December 2018 and, if deemed necessary, further recommendation for improvement made at that stage.

## **Recommendations**

### **Desired outcome – Carers have access to support services that meet their needs**

- (1) It is recommended that Nottingham City Council continue work to explore what activities the local authority can make available to young carers at little/ no cost.
- (2) It is recommended that councillors explore whether ward councillor budgets can be used to fund activities for young carers and if so, identify ways of encouraging councillors to consider this as an option for use of their ward councillor budget.
- (3) It is recommended that Carers Federation and Carers Trust work together to explore opportunities for jointly engaging with GPs on carer issues.
- (4) It is recommended that, in addition to continued signposting to training provided by other providers, Carers Trust explore holding falls and handling training for carers alongside carer support workers.
- (5) It is recommended that Nottingham City Council explore whether access to transport for carers can be incorporated into work being led by the Older Peoples Champion on loneliness.
- (6) It is recommended that Carers Trust trial holding support groups in the evening.

### **Desired outcome – Young people with caring responsibilities are identified at an early opportunity and given access to appropriate support**

- (7) It is recommended that Carers Federation speak to the Nottingham Schools Trust about ways of engaging its primary schools on young carer issues.

### **Desired outcome – Carers are aware of services available to support them in their caring role**

- (8) It is recommended that Nottingham City Council promote carer support services in ward newsletters, with a particular focus on services available in that ward.
- (9) It is recommended that Nottingham City Council explore opportunities for promoting carer support services in The Arrow.
- (10) It is recommended that Nottingham City Council ensure that awareness of carer support services is included in training for homecare workers.

**Desired outcome – There is an efficient way for carers to provide relevant information to inform decision making about support for the carer and the cared for person**

- (11) It is recommended that Carers Trust explore opportunities for sharing information with social care teams to reduce the amount of times that carers need to provide the same information and to share relevant information about carers to inform social care decisions about care packages for the cared for person.

**Desired outcome – The needs of carers are taken into account during decision making on the commissioning and provision of mental health services**

- (12) It is recommended that the Health Scrutiny Committee raise the impact on carers when scrutinising access to mental health services.

## **Contact Details**

If you would like to find out more about this study group and/or health scrutiny in general please contact:

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