Oxfordshire Joint Carers’ Strategy Refresh

2013 – 2016
Introduction

Carers are people who care, unpaid, for friends or family members who are ill, frail or disabled. Carers impact on and are impacted by almost all health and social care services.

As part of the ongoing project to refresh the Joint Oxfordshire Carers’ Strategy, Oxfordshire County Council (OCC), the Oxfordshire Clinical Commissioning Group (OCCG) and their partners, including Carers UK, have been working to better understand the local carer population and to review local support for carers.

A report setting out evidence on carers and caring in Oxfordshire has been compiled. Based on the key findings of this report – including the views of carers, health and social care professionals, and other stakeholders – 7 strategic priorities for the new Joint Oxfordshire Carers’ Strategy have been set.

We would like to consult with the people of Oxfordshire to refine and improve these initial proposals. We are seeking answers to the following questions:

1) Have we got the 7 strategic priorities right?

2) What else should we include and why?

3) Are there any other comments that you would like to make?

Once the priorities are agreed following this consultation, they will be the main focus of the refreshed Joint Oxfordshire Carers’ Strategy and will inform the planning and commissioning of support for all groups of carers across social care and health, including young carers, parent carers and those caring for people with mental health conditions.

National vision for carers

The National Carers Strategy sets out a strategy for improving support for carers over ten years from 2008 to 2018. The vision of the strategy is that carers will be universally recognised and valued as being fundamental to strong families and communities. The strategy was refreshed in 2010 and some further priority areas were identified.

The priority outcomes identified by the National Carers Strategy and 2010 refresh are outlined below, separated under three main outcome areas – service transformation for the local authority and health services, and health and wellbeing for carers, their families and the people they care for.

---

1 Carers and caring in Oxfordshire: Evidence report (2012), Carers UK
Service transformation outcomes

- Carers will be respected as expert care partners and will have access to integrated and personalised service they need to support them in their caring role.

- Personalised support both for carers and those they support, enabling them to have a family and community life.

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.

Health outcomes

- Carers will be supported to stay mentally and physically well and will be treated with dignity

Wellbeing outcomes

- Carers will be supported to have a life of their own alongside their caring role.

- Carers will be supported so that they are not forced into financial hardship by their caring role.

- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.

- Enabling those with caring responsibilities to fulfil their educational and employment potential.

The local position

Oxfordshire Carers’ Strategy 2009-12 Vision Statement

Our local vision is to deliver the National Strategy ‘Carers at the heart of 21st Century families and communities. A caring system on your side. A life of your own’ in response to the needs of carers in Oxfordshire.

Oxfordshire intends to achieve this by working in partnership, by recognising and respecting both adult and young carers in their own right, by training and supporting staff to fulfil the strategy’s aims and objectives, and by working to support carers in their caring roles, in their health and wellbeing and in their wider aspirations.

The Oxfordshire Carers’ Strategy 2009-12 built on earlier strategic aims and objectives while integrating the general direction and vision of the newly
published National Carers Strategy. It incorporated what carers and organisations for carers in Oxfordshire had told us they wanted and needed at the time.

In 2009-10 there was a review of the arrangements to support carers in Oxfordshire, to evaluate the effectiveness of services and to identify opportunities to transform services to make them more effective and personalised. As a result of this review, a new model of carers support was commissioned including Carers Oxfordshire – an integrated information and support service for adult carers of adults.

The evidence collected and analysed through this project demonstrates that the new model is better suited to meeting some key aims and outcomes for carers than the previous model. However, opportunities have been identified to further improve support and provision for carers within both health and social care.

**Key findings from the Carers and caring in Oxfordshire evidence report**

A report compiling evidence on carers and caring in Oxfordshire has been produced as part of our work to refresh the strategy, to help us understand carers in Oxfordshire and what they need\(^2\). This evidence report clearly shows how essential carers and the unpaid care they provide are to the future of social care and health services in the area.

However, it does highlight that there are some groups of carers who are more likely to experience the negative impacts of caring. There are also groups who face barriers to accessing information, advice and support services to help them care and maintain a life outside of caring.

Some of the key findings of the report are listed below.

**Carer identification and support**

- There are large numbers of ‘hidden carers’, particularly people who are early in their caring role and/or have lower intensity caring roles.
- Patterns in the ‘triggers’ for carer identification, including high proportions of hidden carers, combined with the way that carers report they use health services, and are treated by health services, shows that there is a greater role for GPs and other health ‘gateways’ to play in early identification and intervention for carers.
- Carers want a single, high quality and easy to access ‘gateway’ to advice, information and support.
- There are high levels of awareness and acceptance of Carers Oxfordshire, especially in the context of it as a relatively new service.

---

\(^2\) Ibid
Not all of carers’ support needs can be met by carer support services in isolation, because some key needs relate to improving carers’ experiences and involvement in wider social care and health provision.

**Health and wellbeing of carers**

- Caring, particularly unsupported caring, impacts negatively on the health of carers, increasing demand for health services, yet current health services may be treating these health ‘symptoms’ of caring, without identifying and/or addressing the cause.
- Carers in poor health and/or with sustained or high intensity caring roles are more likely to report negative health and wellbeing impacts of caring.
- Older carers are a growing group who are more likely to be in poor health.
- Carers of those with particular conditions could benefit from training to help them manage, e.g. dementia, mental health, stroke and end of life.
- Carers of people with mental health conditions are more likely to report delays in carer identification and negative mental and some physical health impacts of caring. They are also more likely to report difficulties in making choices about their caring, and challenges in accessing appropriate respite support.

**Carer experiences of social care and health**

- All groups of carers highlight good health and social care support for the person they care for and access to appropriate respite and breaks as key support needs.
- Carers report that they would like to have more support through health ‘gateways’ including GPs.
- Carer experiences of using health services, particularly in hospital settings, highlights that many do not feel sufficiently involved in key decisions around treatment and discharge and do not always feel prepared to manage health treatments. Evidence shows this can lead to negative outcomes for carers and patients, and increased demand for services, e.g. hospital readmissions and/or increased demand for GP services.
- Reported experiences of carers demonstrates that they would like to access more information, advice and support from hospitals, GPs and other health settings, including information on support for themselves, as well as on how to manage their own health conditions, and the medical needs of the person/s they care for.
- Carer experiences of health and social care pathways highlight that many feel that existing pathways are not sufficiently integrated or are not clear. The impacts of this can be delays, breakdown in communications and the need to repeat information. This makes it challenging for carers to manage the needs of the person they care for, and their own health and care needs, in an effective way.
- Many carers reported that they did not feel involved or treated as partners in assessments and support planning of the person they care for.
Many carers reported that a key need was improvements in their experiences of wider social care, including timelines and delays around assessments, equipment provision and communication.

**Young carers**
- Young carers experience a range of significant negative impacts of caring, on health, wellbeing and educational attainment.
- Stakeholders report that due to low young carer awareness among relevant professionals, negative 'symptoms' of caring can be acted on, rather than identifying the relevant young person as a carer.
- Young carers and parent carers highlight ensuring successful transition to adult services as a key need.

**Parent carers**
- Parent carers are more likely to report delays in carer identification and are more likely to have sustained and high intensity caring roles.
- Three quarters of parent carers who responded to the survey had children who also provided care and were more likely to be caring for more than one person.
- Some groups of parent carers, e.g. those caring for children with mental health conditions, report barriers in accessing appropriate respite services. They also report barriers to accessing appropriate advice and information to support them in their caring role.
- Some parent carers and other stakeholders commented that services could be improved if parent carers were able to access a wider range of support from Carers Oxfordshire.

**Working carers**
- Working and working age carers report that they need support to help them stay in paid work, including flexible working arrangements.
- Many employees find it challenging to balance paid work and caring responsibilities.
- Employees value flexible working opportunities as a way to help them balance paid work and caring responsibilities.

**BAME carers**
- There may be barriers to some BAME carers identifying as carers and accessing appropriate support. This is due to a range of issues and factors that include cultural differences in expectations and roles within families, which make it less likely that people identify as ‘carers’ or feel it is appropriate to seek outside support, language, and increased difficulty in finding appropriate support and respite services.
What are the priorities for the Joint Oxfordshire Carers’ Strategy?

The proposed priorities are based on the findings of the evidence report set out previously and the views of carers and professionals in Oxfordshire.

A summary of the priorities can be found below:

1. Improving carers’ experiences of health and social care services
2. Giving carers effective support and opportunities for a break
3. Increased carer identification
4. Improving health and wellbeing of carers
5. Helping carers to fulfil their education, employment and training potential
6. Supporting carers through transition
7. Helping those carers who need more support

Priority 1: Improving carers’ experiences of health and social care services

"I really, really enjoyed being part of something that will benefit and support others." --- A carer involved in the procurement process

Carers have highlighted as a key need better services for the people they care for and better experiences of trying to access support. They say there can sometimes be a failure to share information between services or a lack of comprehensive and easily accessible information about what services are available and how to access them. Carers sometimes feel they are not treated as partners in the support of the person they care for.

Improved integration of carer identification and involvement in health and social care services would help to improve these experiences. Carers should be treated as equal partners. We will work jointly towards embedding and integrating carers into wider health and social care delivery.

We are proposing the following actions for achievement:

**Improving carers’ experiences of health and social care services**

- A project to improve carer participation in hospital discharge planning, and helping carers ensure they have the information and advice they need to achieve a successful hospital discharge.
- Improve assessment pathways, including embedding carer participation.
- Look at opportunities to better integrate parent carers into the personal budgets offer, as a way of promoting ease of access and transition to adult services.
- Look at the needs of particular groups of carers who care for someone with a condition on a separate health pathway, e.g. dementia, stroke, mental health.
Priority 2: Giving carers effective support and opportunities for a break

"I have just completed a ‘closing’ call with Mrs N. She wanted to pass on her thanks to everyone who has been involved with support for herself and her husband, which she appreciates very much. She desperately needs a break to recharge and is looking forward to using her grant for some respite care for her husband so that she will be able to do that." --- Call handler on Carers Oxfordshire

A majority of carers tell us that they want more effective support and opportunities for a break to help reduce the stress and other negative impacts of their caring role.

This has been a key focus for Oxfordshire since development of the current Carers Strategy and much has been achieved to date including linking carers up with support that is relevant to them, direct payments for families with disabled children, flexible grants for carers aged 16 and over and supported grants for young carers.

Evidence gathered to date indicates that this is working well but that there are opportunities for improvement. We are proposing the following actions:

Giving carers effective support and opportunities for a break

- Continue and expand our current offer for adult carers on access to personal budgets and flexibility in how they are used.
- Look at opportunities to better integrate parent carers into the personal budgets offer, as a way of promoting ease of access and transition to adult services.
- Clarify eligibility of 16-18 year old carers for grants.
- Ensure that the services we offer are what carers say they want and need.

Priority 3: Increased carer identification

The evidence we have collected suggests that there are still a high proportion of carers in Oxfordshire who are hidden and many who are known are being identified late in their caring journey. We intend to reduce this by identifying more carers earlier in the care pathway.

The impacts of not being identified can be significant for carers. Their own health and wellbeing – including their financial wellbeing and opportunities for employment and training – can be adversely affected.

The impacts for health and social services can also be significant. There may be increased demand for health services due to the breakdown of a carers’ own health and the health of the person they care for. In turn, this can lead to increased demand for social care, if carers are no longer able to provide care themselves.
Issues with carer identification are more of a problem for some groups, e.g. young carers, parent carers, carers of people with mental health conditions and BAME carers.

We are proposing the following actions for achievement:

**Increased carer identification**
- Introduce strategies for greater carer awareness and embedding of carer identification across public service provision, e.g. via training, working with GPs.
- Introduce strategies to embed carer identification in health settings, e.g. hospital discharge practice, use of GP data/records to identify and contact ‘hidden carers’.
- Integrate carer awareness in community outreach work to particular groups/communities, using existing networks of community groups.
- Carers support service will continue to have a focus on outreach work as a way of identifying hidden carers.
- Use of private sector employers as a way of identifying hidden carers in paid work and encouraging continued participation in paid work.

**Priority 4: Improving health and wellbeing of carers**

"I was on a table talking about carers and the carers were sharing information. One of them said how useful it had been talking to someone from Carers Oxfordshire, and then they all agreed that information was the key, that there are services out there to help but too many people don't know about them." --- Val Wilson, Facilitator

Evidence clearly demonstrates that there are negative health and wellbeing consequences for people who care. Carers are significantly more likely to be in poor health – both physical and emotional – than people without caring responsibilities.

Carers also report that caring has negative impacts on their financial wellbeing, primarily by reducing their ability to engage in paid work.

Improving the health and wellbeing of carers has the potential to reduce demand for health and social services, both by the carer and by the cared for person if the carer is well enough to care.

We are proposing the following actions for achievement:

**Improving health and wellbeing of carers**
- Focus on early identification of carers and interventions to prevent negative impacts.
- Focus on integrating carer identification and signposting across health and social care services to encourage provision of consistent and appropriate health advice.
• GPs and health to work to better identify and support carers, including addressing their own health needs (through liaising with GPs, information sessions, carers health development workers etc).
• Supply of appropriate support for carers.
• Information, advice and signposting for carers on financial information and advice, including on accessing relevant benefits.
• Focus on activities around employment and training, including initiatives described under Priority 5.
• Initiatives to target those groups most likely to experience negative health and/or wellbeing impacts of caring including:
  - Young carers
  - Parent carers
  - Carers of people with mental health conditions, including dementia
  - Older carers
  - Carers in poor health
  - Carers providing high levels of care

### Priority 5: Helping carers to fulfil their education, employment and training potential

Evidence demonstrates that caring impacts negatively on participation and achievement in paid work and training. Nationally, carers are less likely to be employed than the general population and this gets worse the more time they spend caring each week. Some carers have to reduce their participation in paid work or training because of their caring responsibilities.

For young carers, caring can have a significant negative impact on educational attainment. They may take time off school because of their caring role and are more likely to leave school early than their peers.

We would like to see all those with caring responsibilities able to fulfil their education, employment and training potential and are proposing the following actions to help achieve this:

#### Helping carers to fulfil their education, employment and training potential

- Continue and look at extending, if appropriate, personal budgets for education and training purposes.
- Oxfordshire Employers for Carers has been commissioned and will work directly with local private sector employers to identify and support their employees with caring responsibilities.
- Focus on what young carers need and initiatives to facilitate participation in training and paid work.
- OCC and OCGG/health will undertake initiatives in their roles as employers including membership of Oxfordshire Employers for Carers.

### Priority 6: Supporting carers through transition
Making transitions as carers progress through their ‘caring journey’ can be stressful and uncertain times for carers and the people they care for. Carers can be ‘lost’ to support if not effectively supported throughout their ‘caring journey’

Transition to adult services is relevant to
- Parent carers, whose child is transitioning to adult services
- Young carers, who are transitioning to adult services

Transitions to adult services need to be carefully managed and planned, to ensure those involved in the process feel supported and do not drop out of services or feel they are no longer able to cope. In the case of young carers, it is also necessary to ensure that adult services effectively meet the needs of young adult carers.

When the caring role comes to an end is also a time of change and transition for carers. For some carers, their caring role ends due to the death of the person they care for, they may need support dealing with bereavement. Other relevant support includes education and training to support carers back into paid work and support reconnecting with family, friends and communities.

We are proposing the following actions for achievement:

**Supporting carers through transition**
- Ongoing activities to support parent carers through transition.
- Expand offer to parent carers from Carers Oxfordshire as a way of promoting ease of access and transition to adult services.
- Introduce initiatives to improve young carer transitions, including tying in with educational opportunities.
- Ensuring effective support for those whose caring role has come to an end, including bereavement support, education and training opportunities.

**Priority 7: Helping those carers who need more support**

Some groups of carers are more likely to experience the negative impacts of caring than others, including negative health and wellbeing impacts and/or barriers to accessing services.

Relevant groups are likely to include:
- Older carers
- Carers in poor health
- Carers of people with mental health conditions, including dementia
- BAME carers
- Young carers
- Parent carers
- Carers providing high levels of care

We are proposing the following actions for achievement:
Helping those carers who need more support

- Some initiatives will need to focus on improving access to services.
- Some initiatives will need to focus on targeting tailored services to certain key groups.
- Some carers caring for people with particular conditions may benefit from training and support, e.g. dementia training. There could also be training around mental health, stroke, incontinence, end of life or other priority areas.