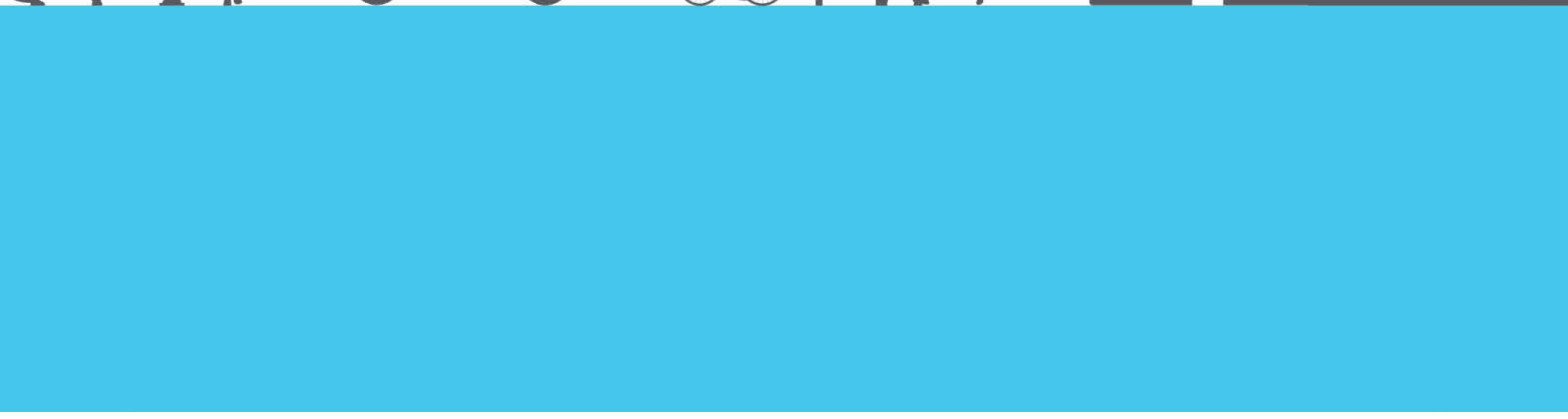




# The Health and Wellbeing of Unpaid Carers:

## Where Can Digital Skills and Community Support Add Value?



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# 1. Forewords

## Helen Milner OBE, Chief Executive, Tinder Foundation

At Tinder Foundation, we're committed to supporting people to gain the skills they need to benefit from digital technology. We've seen first hand the huge impact technology can have - whether through helping people to save time, learn something new or even to save money.



Through our extensive work supporting people to improve their skills - and particularly through our local network of partners - we know just how important digital skills can be for carers too, which is why we created a Specialist Network to support local organisations working with carers.

To support the network, this report aims to show how by working with partners in the sector we can use digital technology to support carers, who are often working tirelessly providing unpaid care, something that can have a significant impact on their health and wellbeing.

I'm delighted we've been able to work with Carers Trust, Carers UK and Family Fund to put together this research, which makes a really strong case for the huge potential role digital can play for carers.

Thanks to all who helped put this report together. The findings are clear - now we need to continue working together to plan activity to ensure digital can continue to make an impact on the lives of carers.



## Madeleine Starr MBE, Director of Business and Innovation, Carers UK

Caring increasingly affects us all at some point in our lives, whether we find ourselves looking after someone we love, or we need some support ourselves. However, caring without enough support in place can have a huge impact and it is taking its toll on millions of families throughout the UK.

Carers UK works to improve the lives of carers by offering expert advice, information and support.

We are working closely with carers who often tell us that they don't have the time or energy to maintain relationships, stay in work, or look after their own health and wellbeing.

We were pleased to support this important piece of research led by Tinder Foundation and to help raise awareness of the pressures of caring and the need for timely, practical and targeted support that can alleviate its stresses.

## **Cheryl Ward, Chief Executive, Family Fund**



We know that being a carer can be physically and emotionally draining. Every year Family Fund supports tens of thousands of parent carers with grants which help ease some of the daily pressures of caring. Parents tell us they experience a range of pressures from suitable childcare to flexible working arrangements and the day-to-day impact on home life, particularly sleep.

The more we know, the better we can help. The results particularly highlight the prevalence of isolation amongst carers and the importance of maintaining carers' wellbeing and resilience - issues we will continue to advocate for action on. We have welcomed contributing to this project and ensuring parent carers have been able to give their views, and we hope it will raise awareness amongst others to improve the support and information available to carers.

## **Michele Lambert, Head of Digital, Carers Trust**

Carers Trust was delighted to be involved in research for this project. Looking after someone else's needs can impact carers' physical and mental health and time spent caring can often detract from spending time with friends and pursuing social activities.

Digital technologies have a powerful role to play in reducing the feelings of isolation that many carers experience, allowing them to connect with others in a similar position, find friendship and access information and support when they need it most. Carers of all ages tell us this can be a lifeline. For those that do not live near a local service or who are unable to leave their home due to the demands of their caring role, the internet can open a new window on the world, giving access to advice and peer support wherever they are in the UK.



Carers Trust helps carers via a UK-wide network of quality assured independent partners which deliver a range of local support services for carers, according to need in their communities and via online support services, which offer age-appropriate and confidential support in a safe environment, moderated by a team of qualified youth, community and social workers.

With the estimated 7 million carers in the UK forecast to rise to 9 million by 2037, it is more important than ever to focus on sustainable support models that can reach as many carers as possible, improving their daily lives and wellbeing.

## 2. Executive Summary

Between April and June 2015, in partnership with Carers Trust, Carers UK, Family Fund and local partners in the UK online centres network who support unpaid carers, Tinder Foundation led a short research project to better understand:

1. How caring roles affect individuals' health and wellbeing
2. What role digital can play in helping carers
3. The barriers to social and digital inclusion faced by unpaid carers
4. The current support models delivered by partners in the UK online centres network, as well as other national and local partners
5. The role Tinder Foundation, the UK online centres network and other specialist organisations have in addressing identified issues and co-producing and delivering future digital and local support

### Key Findings

#### Finding 1: Unpaid caring is a hidden issue

Although an estimated 6.5 million people in the UK provide unpaid care, many don't necessarily see themselves as carers, therefore national and community organisations don't feel they are reaching as many carers as they'd like with information and support. In addition, a large proportion of carers don't feel valued or understood. In a 2014 Carers UK survey, nearly half said they feel society does not think about them at all<sup>1</sup>, [making caring a hidden issue](#).

#### Finding 2: Caring leaves little time to focus on own health

With those surveyed having a considerably lower health and wellbeing score against the national average (18.9 versus 23.6<sup>2</sup>) and 20% of carers considering themselves to have a mental health condition, it's important carers receive the support they need to help them look after themselves. However 29% of carers tell us they have [little time to focus on their own health](#), which isn't surprising as 77% surveyed undertake more than 50 hours of caring a week.

#### Finding 3: Carers are missing out on a life of their own

[Carers told us that they feel their lives have been put on hold](#) and they are missing out on things that are key to good health and wellbeing, such as a social life and work. 46% of carers are not in work and not looking for work, and of those who are working, or looking for work, 89% say caring limits their capacity for paid employment. 40% of carers say they rarely or never feel optimistic about the future, and parent carers worry especially about the future care of their children.

#### Finding 4: Carers feel unsupported

[One of the biggest challenges carers say they face is a lack of support](#) - financial, practical and emotional support. Many are resigned to the fact they have to take on the burden of caring alone, feeling family, friends, society, the health and social care system don't understand

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<sup>1</sup> Carers UK (2015) [Facts about carers](#)

<sup>2</sup> Using the Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)

what it's like. One of carers' main worries is their capacity to look after the person they care for well enough. Carer confidence is affected by lack of timely information and support, with many carers feeling local organisations aren't working together to deliver such support. On top of this, carers often lack any emotional support. Not knowing where to get support is a problem, especially for individuals who are new to caring, with 17% of carers saying they don't know where to go, and 29% saying there is a lack of support available.

### **Finding 5: Carers are benefitting from digital technology and local support**

Of the carers surveyed, **92% use the internet several times a day or daily, 81% are shopping online, 74% are keeping in touch with friends online, and 69% are banking online.** Carers value the internet for enabling social connection and emotional support through online communities, are researching health conditions and finding information to help with their caring responsibilities online. Local organisations like UK online centres and Carers Centres are already providing an essential service in promoting the benefits of being online to carers (See Appendix 1) but generally there is little use of the internet by carers to manage their own health and wellbeing (11%)

### **Finding 6: Digital exclusion is a key issue amongst carers**

Although many carers are benefitting from digital technology, digital exclusion is still a key issue. We know that socially excluded people such as those of low economic status, of older age and with a disability are more likely to be digitally excluded. Many carers fall into these categories and therefore **many carers are missing out on the benefits the internet can bring.** Only 15% of survey respondents use the internet to claim benefits online, and only 31% to save money online.

## **Recommendations**

Our research has helped us to put together the following recommendations for how digital technology and local support can be developed to help carers more.

- 1. Raise the profile of caring** through embedding carer stories into well-used websites, signposting to local support services and providing advocacy support to carers. Local and national organisations should continue to work in partnership to raise the profile of carers within their networks and use volunteers as a way to reach unidentified carers.
- 2. Support carers to focus on their own health** by promoting the use of digital tools to save time<sup>3</sup> and make life easier, through recommended health and wellbeing resources and digital peer and emotional support platforms.
- 3. Empower carers to take control of their lives** through recommended digital tools to help carers maintain friendships, pursue interests and maintain and develop new skills.

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<sup>3</sup> By accessing government services and online banking transactions online, individuals can save an average of 30 minutes per transaction ([The economic impact of Basic Digital Skills and inclusion in the UK](#) A report for Tinder Foundation and GO ON UK, November 2015)

- 4. Raise awareness of support that fits around carer demands** through easy access to online portals (like [Carers Hub Lambeth](#)<sup>4</sup>) with bespoke local carer information and guidance (e.g. benefits entitlements and how to save money<sup>5</sup>), with trusted, recommended resources and eLearning to keep carers up-to-date on carer best practice and expertise.
- 5. Create the conditions for blended support** by encouraging local organisations such as Carers Trust Network Partners to join the UK online centres network<sup>6</sup>, work in partnership with a local UK online centre<sup>7</sup> or integrate digital skills training into their support model by training volunteers or centre staff to become Digital Champions and to share the benefits of digital technology with fellow carers.
- 6. Reduce digital exclusion amongst carers** by working in partnership at a national and local level to campaign for support to help carers overcome barriers of access, motivation and skills, through online learning platforms to help carers develop digital skills (such as staying safe online and using online forums), lobbying for cheaper home access options for carers and raising awareness of affordable home access options on offer.

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<sup>4</sup> With responsibility falling to local authorities to offer appropriate information and guidance under the [Care Act 2014](#), local authorities are starting to develop ways to deliver IAG to carers digitally

<sup>5</sup> Evidence shows that shopping online saves individuals on average 13% compared to if they were to shop in-store, equivalent to £143 per person per year ([The economic impact of Basic Digital Skills and inclusion in the UK](#) A report for Tinder Foundation and GO ON UK November 2015)

<sup>6</sup> The UK online centres network is the biggest digital inclusion network in the country. It brings together more than 5,000 organisations and 25,000 volunteers working in their communities to help people develop their digital skills. Benefits include access to an online learning platform, management data, forums, training and inclusion in national campaigns (<https://www.ukonlinecentres.com/join-the-network>)

<sup>7</sup> Find a UK online centre on Centre Search (<https://www.ukonlinecentres.com/about-us/centre-search>)



### 3. Introduction

A carer is someone who provides unpaid care for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support<sup>8</sup>. In the UK in 2015, 6.5 million people provide unpaid care, 1.4 million people provide 50 or more hours of unpaid care a week<sup>9</sup>, and 3 million people are combining caring with work.<sup>10</sup> Unpaid carers provide support for some of the most vulnerable people in our society and need support and recognition as they carry out this work.

Due to the pressures and constraints of their caring role, unpaid carers are often limited in their capacity to engage with paid employment or participate in social activities, while the 38% of carers in full-time employment feel isolated from other people at work because of their caring responsibilities, and as such are at risk of developing poor mental health.<sup>11</sup>

To date, the role of digital tools and development of digital skills as part of a blended support solution for carers has been little understood<sup>12</sup>. The UK's leading digital inclusion organisation, Tinder Foundation, is committed to helping people who could most benefit from digital skills and support, and with many services moving online as part of the government's digital by default agenda<sup>13</sup>, we want to better understand the situation facing carers. So between April and June 2015, in partnership with Carers Trust, Carers UK, Family Fund and local partners in our UK online centre network supporting unpaid carers<sup>14</sup>, we led a short research project to better understand:

- 1. How caring roles affect individuals' health and wellbeing**
- 2. What role digital can play in helping carers**
- 3. The barriers to social and digital inclusion faced by unpaid carers**
- 4. The current support models delivered by partners in the UK online centres network, as well as other national and local partners**
- 5. The role Tinder Foundation, the UK online centres network and other specialist organisations can have in addressing identified issues and co-producing and delivering future digital and local support**

8 out of 10 carers have felt lonely or isolated as a result of caring, with 55% of carers reporting they are not able to get out of the house much (rising to 64% for those caring for 50 or more hours a week). 61% don't have time to participate in social activities, a situation exacerbated for the 45% not able to afford to participate in social activities. 54% of carers are struggling to pay household bills and 35% are cutting back on essentials like food and heating to make ends meet.

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<sup>8</sup> Definition based on information provided by Carers UK, Carers Trust and Family Fund

<sup>9</sup> Carers UK (2015) [Facts about carers](#)

<sup>10</sup> ONS (2011) [Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001](#)

<sup>11</sup> Mind (2014) [How to cope as a carer](#)

<sup>12</sup> This research project builds on previous research undertaken by partners, including Carers Trust's 2011 report [How the web can help carers](#).

<sup>13</sup> GDS [About the Government Digital Service](#)

<sup>14</sup> Detailed descriptions of all Research Partners can be found in Appendix 1



Potential circles of support also suffer, with carers often feeling isolated from family and friends who do not share the same circumstances. As a result, 36% are not comfortable talking to friends about caring and 57% have lost touch with friends and family as a result of caring. Likewise 49% of carers say they have experienced difficulties in their relationship with their partner because of their caring role.<sup>15</sup> In turn this can have considerable impact on both their ability to care for themselves and the individual they care for.

*"Caring has affected my health; I have got fibromyalgia. I lack spontaneity, I can't make any plans and I am always late. People don't understand - I am managing different households. What is my future like? What will happen to me because I spend so much time looking after someone else?"*

**Parent carer of disabled child**

## Research Approach

The research methodology combined deep dive qualitative and quantitative data collection and analysis. We held 7 focus groups with 40 carers with differing levels of computer and internet use attending UK online centres and Carers Trust Network Partners. We carried out 9 interviews with carer support organisations, collected the views of 1802 carers<sup>16</sup> through an online survey administered by Carers UK and Family Fund, and held 2 webinars to discuss emerging research findings with partner organisations.

A programme of grant-funded participatory activity was designed to support the engagement of Research Partners (local centres in the UK online centres network which support carers) in order to collect qualitative data. The distribution of these centres can be found in Appendix 2 and a more detailed Timetable of Research Activities can be found in Appendix 3. Our Research Partners were:

- 1. Liverpool Carers Centre** (a Carers Trust Network Partner)
- 2. North Lincolnshire Carers Support Centre** (a Carers Trust Network Partner)
- 3. Lincs Training**
- 4. City and Hackney MIND**
- 5. North Bradley Peace Memorial Hall**
- 6. Age UK Hereford and Localities**

To measure the health and wellbeing of carers taking part in the research, we used the Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)<sup>17</sup> which is a scale of 7 positively worded items, with 5 response categories, for assessing a population's mental wellbeing.

The following section presents the findings from the research.

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<sup>15</sup> Carers UK (2015) [Alone and Caring: Isolation, loneliness and the impact of caring on relationships](#), Statistics taken from Carers UK's State of Caring Survey 2014 of over 5,000 UK carers.

<sup>16</sup> The ages of carers completing the online survey ranged from under 16 to 65+

<sup>17</sup> The Warwick-Edinburgh Mental Well-being Scale was funded by the Scottish Executive National Programme for improving mental health and well-being, commissioned by NHS Health Scotland, developed by the University of Warwick and the University of Edinburgh, and is jointly owned by NHS Health Scotland, the University of Warwick and the University of Edinburgh.

## 4. Thematic Findings

### Finding 1: Unpaid caring is a hidden issue

In 2014, half of carers (49%) said they feel society does not think about them at all<sup>18</sup>.

- Those looking after a friend or family member often don't see themselves as carers.
- Organisations can feel they aren't reaching all carers, especially younger ones.
- Caring and its impacts aren't given the national profile they deserve.
- Worry about the stigma attached to caring, pride and feeling guilty for asking for help can stop carers identifying with messages of support.
- Negative stereotypes placed upon disabled people and people with health conditions can have an indirect impact on the health and wellbeing of carers.

*"People call me a carer but I don't necessarily see myself as one. She's just my friend - I'm a carer by default".*

**Carer, age 55+, cares for friend who she lives with**

Caring can affect individuals and families at any point, making them a difficult group to identify and target. The age of carers ranges hugely with the peak age for caring between 50 and 64 years (one in five people aged 50-64 are in an unpaid caring role<sup>19</sup>). The majority (66%) of carers who took part in our survey are caring for one person. Carers are looking after:

- **Spouses/partners** (most commonly those under 65)
- **Parents and parents-in-law** (most commonly those over 65)
- **Disabled or ill children**
- **Siblings and siblings-in-law** (most commonly those aged under 18)
- **Friend(s)**
- **Other family members** (most commonly those under 18) including grandchildren, foster children, step-children, ex-partners and other family members such as aunts and uncles.

But carers in our study, of all ages and circumstances, felt that caring is not given the profile it deserves, and that society, government, health professionals and even friends and family don't recognise what being a carer involves, and the impact it has on an individual's health and wellbeing. Although some carers noted the profile of carers has been raised since the 2014 Care Act<sup>20</sup>, common opinion was that it hasn't gone far enough, and there is a general lack of political support felt amongst unpaid carers. Those that care feel the knock-on effect of this, describing life as a battle to get support, feeling they are not being listened to or

<sup>18</sup> Carers UK (2015) [Facts about carers](#)

<sup>19</sup> Carers UK (2015) [Facts about carers](#)

<sup>20</sup> Carers UK (2015) [Care Act FAQ](#)

involved in discussions about the health of those they care for, and are not being asked enough how they are feeling.

In a 2011 Carers UK survey, although 84% of the carers who were caring for at least 50 hours a week had a GP who knew of their caring responsibilities, 71% said that their GP didn't do anything differently to accommodate them. Very few had a GP who gave regular carers health checks or did home or telephone appointments<sup>21</sup>.

Pride, not feeling entitled to support and not wanting to admit one can't cope can be barriers to carers seeking support, especially amongst older people. Anecdotal evidence suggests that a fear of being judged by peers, family and health professionals is common amongst carers. Young adult carers<sup>22</sup> often feel they don't deserve support as they feel their caring situation isn't always a bad one. Some also report that support services assume they can cope. However, younger carers can face confidence and self-esteem issues, making it even harder for them to seek support

*"I always worry that people will think badly of me for not coping or that I am making a mountain out of a molehill"*

**Single mum, aged 25-34, cares for child under 18 years**

With many carers not considering themselves as such, national and community carer support organisations know they are still not reaching those that could benefit from support the most.

Our research found that society's views on disabled people and people with health conditions also causes a lot of stress and apprehension for carers. This is backed up by research carried out by Carers UK in 2014, which found evidence of discrimination and prejudice faced by families affected by disability<sup>23</sup>. These negative experiences (including feeling excluded from public places that don't cater for people of all abilities) can lead to negative impacts on the health and wellbeing of carers.

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<sup>21</sup> Carers UK (2015) [Facts about carers](#). Reference taken from Carers UK (2011) State of Caring 2011

<sup>22</sup> Young adult carers are young people aged 16–25 who care, unpaid, for a family member or friend with an illness or disability, mental health condition or an addiction (definition provided by Carers Trust)

<sup>23</sup> Carers UK (2015) [Facts about carers](#)

## Finding 2: Caring leaves little time to focus on health

**20% of carers consider themselves to have a mental health condition yet 58% don't get support to manage their health and wellbeing**

- Carers find it hard to plan ahead due to the unpredictable nature of caring, leaving them feeling behind and frustrated.
- Carers lack time to get everything done - 22% care for two people and 77% undertake 50+ hours of caring a week.
- One of the biggest challenges for carers is feeling tired as a result of lack of sleep and/or broken sleep.
- Carers need respite but this is either lacking, or hard to find.
- Carers are more concerned about the health and wellbeing of those they care for than their own.
- The biggest barriers to getting health and wellbeing support are a lack of awareness of who and where to get it from, and the belief that there isn't any support out there.

*"Days being housebound make you feel low, lonely, frustrated, distressed, stressed, and anxious. - knowing that there really is no alternative and feeling like you have no time to think about yourself as carer and concentrate on your own health by putting the needs of the cared-for person first."*

**Mum, aged 35-44, caring for child under 18 years old**

Caring is more than a full-time job and the type of care individuals provide varies considerably. The impact of caring on carers' health and wellbeing also varies for each carer, but is significant. On average, carers responding to our survey recorded a considerably lower health and wellbeing score compared to the national average (18.9 versus 23.6<sup>24</sup>). This score includes ratings for optimism for the future, feeling useful, feeling relaxed, dealing with problems well, thinking clearly, feeling close to other people and being able to make one's own mind up about things.

26% of carers reported they never felt relaxed, a further 46% rarely feeling relaxed, and 15% felt they had no close relationships from which they could draw support. In addition, 20% of carers consider themselves to have a mental health condition and 15% consider themselves to have a condition that limits basic physical activity. Of those, 48% say it has a substantial adverse effect on their ability to carry out normal day-to-day activities.

With 77% of carers responding to our survey undertaking more than 50 hours of caring a week, it makes sense that carers tell us they have little time to focus on their own health. Being pulled in different directions, not knowing what's going to happen from one minute to the next and difficulty planning ahead are contributing factors to 29% of carers saying they lack time to seek health and wellbeing support. And many carers work on top of caring - 22% work part-time and 10% work full-time - so can lack time to process the large amount of

<sup>24</sup> Using the Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)

information coming their way, and to keeping organised. The group most likely to get health and wellbeing support are those aged 65+ and those least likely are those aged 35-44.

*"Just having to be so organised all the time can be draining - making sure I don't miss any appointments at the hospital, dentist, and doctors. It's hard with two other children to care for on top of being an older mum, and having just been diagnosed with emphysema myself."*

**Mum, aged 55-64, caring for child under 18 years old**

Carers' biggest priority is the health and wellbeing of those they care for, rather than their own, but our research revealed that many feel they need to learn to look after and create space for themselves in order to continue caring. Carers that are getting health and wellbeing support are getting it from family (65%), friends (40%), community organisations (30%), social services (26%) and online resources or websites (11%). But many carers feel that family and others don't understand what it's really like. Community organisations tend to be a more common source of support in the over 55 age group than for the younger demographic, who tend to seek support from friends and family.

When asked about using the internet for their health and wellbeing, carers found this difficult to answer. Although many carers do use social media and forums as a way of connecting with others, most found it difficult to relate this specifically to their own health and wellbeing. 61% couldn't think of any online resources or websites to help them manage their health and wellbeing that they would recommend to others.

The majority of the carers that we spoke to know that getting out of the house, exercise and talking to others (especially other carers) helps them to manage their health and wellbeing, and that where available, trusted and appropriate respite makes this more possible. But respite can be hard to come by, and trusted respite even more so, meaning that carers worry about leaving the person they care for, as they feel guilty or selfish. In addition, guilt from not feeling they are looking after their other dependents as much as they would like to can affect close relationships, from which they might normally seek emotional support.

## Finding 3: Carers are missing out on a life of their own

### 40% of carers say they never or rarely feel optimistic about the future

- Caring is more than a full time job, often leaving carers little or no time for paid employment or a social life.
- Those that care have little time for themselves or to do what they enjoy, and relationships can suffer leaving them feeling isolated.
- Working age carers can feel their own career and life aspirations are gone.
- Carers lack time and opportunity to maintain their skills and confidence.
- Carers worry about the future - their own future and the future for those they care for.

*"Being a carer is not a normal life, I'm always pulled away from normal activity like working and having free time."*

**Carer, aged 50-60, cares for mother**

The peak age of caring often coincides with the peak of an individual's career in their 40s-60s. Over 2 million people have given up work at some point to care for someone, and over 3 million have reduced their working hours.

From our survey, we found that:

- **46% of carers are not in work and are not looking for work.**
- **22% of carers are part-time employed (less than 30 hours a week) and only 10% are in full-time employment.**
- **For those that see themselves as carers, many refer to their employment status as 'Full-time carer'.**

Some carers are juggling care with a job. Of carers in employment, 86% say caring limits the type and/or amount of paid employment they can do. Of those in part-time employment or unemployed and looking for work, 89% say caring limits their capacity for paid employment. Furthermore, caring can have a long-term impact on an individual's confidence and their ability to work, as a loss of skills, knowledge and experience make returning to work if and when caring ends extremely challenging. On top of this, some carers can find it hard to keep hold of a job as few employers provide flexible working hours or accept that the carer may have to take time off at short notice.

Carers are also at risk of becoming isolated as a result of their caring responsibilities, due to a lack of understanding about their caring role amongst friends and family, exacerbated by changes such as leaving work and losing touch with friends, colleagues and families because of restrictions over their free time. 57% of respondents to Carer's UK's State of Caring 2014 survey said they had lost touch with friends as a result of caring, and almost half attributed this to a lack of practical support to enable them to socialise.<sup>25</sup> This isolation is made even

<sup>25</sup> Carers UK (2015) [Facts about carers](#)

worse, with - according to our survey - 31% of carers living with no other adults, resulting in 51% of carers saying they never or rarely feel close to other people. These feelings of isolation are often felt even deeper in rural areas where populations are scattered and public transport links are less established.

*"My own future - jobs and aspirations are gone. I could do with my own long term objectives. Caring is very short sighted for the carer."*

**Carer, age 35-44, caring for child aged under 18 years old**

With the financial implications of not working, the additional costs of caring<sup>26</sup> and the effect on social connections, it's not surprising that 10% of carers say they never feel optimistic about the future, and 30% rarely. Through surveys and focus groups we found younger carers feel their future is put on hold leaving them feeling in limbo (in terms of their own career progression, maintenance of hobbies and interests and a social life). Older carers can feel there is no future for them to plan as they put all of their energy into the care of someone else. Where the carer is older than the person they are caring for, there is real worry around what will happen to the cared for person in the future.

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<sup>26</sup> Many carers also face additional costs such as childcare and care equipment. The cost of raising a disabled child can be up to three times as much as raising other children (Reference taken from Contact A Family 2012 blog ['Counting the costs'](#))



## Finding 4: Carers feel unsupported

### The biggest challenge carers say they face is lack of support

- Support needed by carers includes practical, financial and emotional support.
- Many are resigned to the fact they have to take on the burden of caring on their own, feeling family, friends, society and the health and social care system don't understand what it's like.
- One of carers' main worries is their capacity to look after their family member or friend well enough.
- Carer confidence is affected by lack of timely information and support.
- Many carers feel local organisations aren't working together to deliver this timely and tailored support when they need it most.

*"I don't know where to turn to to get help. It often seems you need to find the help yourself, usually through a learning curve or trial and error."*

**Carer, aged 35-44, caring for child aged under 18 years old**

Carers have different needs, and support means different things to each individual. For many carers, support is seen firstly as information about how to look after the person they care for, including practical and financial support. Most carers haven't received training to look after the health, safety and the affairs of someone else, leading to worry amongst some about their capacity to look after someone else well enough to suit their needs. But what came out of this research was that carers really value (and often feel they are missing out on) emotional support - a listening ear and a shoulder to cry on.

*"It is easy to offer a hand when it comes to giving a short break, but maybe the carer just wants to sit and cry, to be held and told everything will be OK and not to keep on putting on a brave face and pretending just to keep others happy."*

**Single mum, aged 25-34, caring for child under 18 years old**

But not knowing where to get support from is a problem, especially for individuals who are new to caring, with 17% of carers saying they don't know where to go for support, and 29% saying there is a lack of support available. Not knowing where to get support and information came out strongly in our focus groups, with many describing the process as trial and error, citing multiple situations where they wish they had known about certain support earlier.

Where support exists, it doesn't always fit in with carers' life patterns and demands placed upon them, in terms of available timings and locations. Many feel that local organisations aren't working together in a joined-up way - that support has to be known about and sought from a variety of different sources, and that it is not always tailored to individual needs. In association, carer organisations know that getting information and support to carers when they need it is one of their biggest priorities. But with many of these organisations facing funding cuts, how can more carers be reached with support before they hit crisis point?

## Finding 5: Carers are benefitting from digital technology and local support

Of those surveyed: 81% of carers shop online, 74% keep in touch with friends and family online, and 69% bank online

- Carers value the internet for enabling social connection and providing emotional support through online communities.
- Carers are researching health conditions and finding information to help with their caring responsibilities online.
- Tablets are an easy way for carers and those they care for to benefit from online entertainment such as games and sharing photos.
- 92% of carers use the internet several times a day or daily.

*"I use the internet for aspects of living, buying items, form filling, applications for everything and anything, paying bills, shopping around to get best deals, to save time and to still feel like I'm in touch with the world socially even though I am pretty much restricted to what I can do and where I can go."*

**Mum aged 35-44 looking after disabled child under 18 years old**

Where carers in our research are using the internet, there are clear benefits. The internet saves carers' time<sup>27</sup> (7 out of 10 online carers say that the internet saves time<sup>28</sup>) and makes life more convenient through online activities such as shopping and banking online<sup>29</sup>, as carers often keep irregular hours and are restricted to when they can go out. Tablets are convenient for carers and also for the people they care for. In summary, carers are using the internet to:

- Seek information to aid their caring responsibilities via trusted websites and blogs relating to specific health conditions and carers rights e.g. GOV.UK, National Autistic Society website and Google for researching and help with decision making.
- Access emotional support from like-minded people through specific forums on Facebook (of those that use online resources to help manage health and wellbeing, 30% use Facebook) and chat rooms.
- Keep in touch with friends and family via social networking such as Skype.
- Entertain themselves and those they care for, e.g. through games, film, music, eBooks and family history.
- Access health and fitness websites, apps and tools, such as NHS Choices

<sup>27</sup> By accessing government services and online banking transactions online, individuals can save an average of 30 minutes per transaction ([The economic impact of Basic Digital Skills and inclusion in the UK](#) A report for Tinder Foundation and GO ON UK November 2015)

<sup>28</sup> Carers Trust (2011) [How can the web support carers?](#)

<sup>29</sup> Evidence shows that shopping online saves individuals on average 13% compared to if they were to shop in-store, equivalent to £143 per person per year ([The economic impact of Basic Digital Skills and inclusion in the UK](#) A report for Tinder Foundation and GO ON UK November 2015)

*"I use various websites and internet forums - principally through Carers UK, my local internet forum via Carers Trust and I also have a network of 'e-mail friends' - we support each other. Just knowing you can say what you really feel to someone makes you feel better."*

**Carer aged 65 who works part-time, looking after husband and disabled child over 18**

There is a wealth of digital information and support in existence, aimed specifically at carers. Carers UK directly supports carers through their website, online forum (which has 3,000 users), online campaigns and online Q&A sessions e.g. through Facebook. Carers Trust has several websites for different audiences. [Carers.org](http://Carers.org), [babble.carers.org](http://babble.carers.org) and [matter.carers.org](http://matter.carers.org) are UK wide help and support services, provided directly to carers, and staffed by a team of qualified social, youth and community workers to provide fast, age-appropriate and confidential support.

### **Case Studies: Carers Getting Support with Digital**

There are lots of examples of good practice where digital is already having an effect on the lives of carers in local UK online centres. Many centres provide flexible, drop-in support within walking distance for carers, where tablets can be brought to sessions. Carers are learning how to keep in touch with friends and family online as well as skills for jobs, such as CV writing, with people they trust.

#### **Making good things happen with digital technology: Gill Brooker, Lincs Training**

**Gill Brooker is a full-time carer for her husband, Tom, who has dementia and Parkinson's disease. Since attending her local community centre and UK online centre in Louth, she's been able to make new friends, get online and finds it easier to keep in touch with relatives.**



When her brother gave Gill Brooker an iPad, she needed a helping hand getting started with it. With her family dotted around the country and unable to help in person, she decided to try out the free IT classes at her local community centre, Trinity Community Centre, where UK online centre, Lincs Training, is based.

“I met the tutor Rich [Avison] at the computer classes and he’s very good,” explains Gill. “I take my iPad with me to the centre and log on to their WiFi. It’s like learning a new language - so many different terms to take in!”

Gill’s been going to the community centre for years with her husband Tom, who has dementia and Parkinson’s disease.

Gill says: “I’m the kind of person who likes to go out and meet people. Someone told me about a little exercise class and a fish and chip meal that happens every Friday at Trinity, so we decided to go along.

“We’ve been going for a while now and we do lots of different activities. Jayne Pegg, who works at the centre and organises the activities, is a wonderful lady. She comes up with such amazing ideas.”

It was Jayne who decided to start up the local dementia cafe that meets at the community centre once a week. Gill explains: “Jayne could see that there were quite a few people with dementia coming to the different groups with their carers, and she knew there were no facilities to support them in Louth.

“It’s the carers that need support more than the patients really. The patients are being looked after, but there’s no one to look after the carers themselves. When you’re a carer you can’t just go out and do anything you want to.”

The group, called ‘Memories Matter Dementia Cafe’, has been really popular, with around 18 attendees most weeks. Gill says: “It’s absolutely vital for community organisations to support carers. It’s such a dreadful illness and it’s all coming to the forefront now because really famous people, and young people in their 30s and 40s are getting it.

“The computer is one of the most vital things because there’s two or three really good websites out there that provide support for carers.”

Gill uses her iPad to chat to people and get support on the Alzheimer’s Society website. She says: “It’s all like-minded people on there and you can learn so much from it - that’s the most important thing for me.

“I mainly use my iPad to communicate with people. I keep up with my family by email and on Facebook, and I’ve taken a few photographs too. I’m even in touch with a friend in Australia, which is brilliant!

**Attending the centre and learning to use the iPad has really benefitted Gill. She says: “It’s given me confidence. I’ve passed the word around and quite a few of my friends**

**have gone to get some advice and help too. They're so good at Lincs Training. You can just go in and see them and they'll tell you what you want to know.**

"My husband doesn't do anything with the computer at all - he doesn't like them - but we can do other things together at the community centre, like baking bread buns or going on days out. He was an artist before he retired due to ill health, and he would exhibit his work all over, but he can't do it now, which is really distressing for him. That's why I like him to go to different groups at the centre - to keep his mind occupied.

**"The thing is with this illness, it progresses and never gets any better. Community organisations like ours are vital to support carers and patients - we just need to get the word out there!"**

### **Making good things happen with digital technology: Karen Whattam, Lincs Training**



**When she found herself without a job, Karen Whattam from Louth, knew it was time to try something new. Karen is a carer for her mum and thanks to her local UK online centre, Lincs Training, she's been able to balance being a carer with learning digital skills.**

Having never needed to use a computer before, Karen Whattam was lacking the basic digital skills she needed. With a little encouragement from the staff at her local community centre, Trinity Community Centre, she decided to attend some IT classes to help her get online.

"I decided to go along to Lincs Training, based at Trinity," explains Karen. "I initially went to get some advice and see how I would get on at the drop-in, but I also wanted to make some new friends. It went so well, I've been going ever since!"

Attending the classes has really benefitted Karen, who does a lot of voluntary work, as well as caring for her mum who has Chronic Obstructive Pulmonary Disease (COPD). She says: "I hadn't switched a computer on that much before but I've learned lots of skills since going to the centre. I've gained a lot more confidence in myself and my communication skills have got better too."

Karen's new-found knowledge has also helped her do more in her voluntary positions. "I've volunteered at several different places," she says. "I worked at Lincolnshire Community Voluntary Service at Manby, which enabled me to put my skills to the test and work with their computers.

Being a carer means that there isn't always time to go out job hunting, something which Karen would really like to do. Thankfully, Richard and Tony, the tutors at Lincs Training, have been able to make finding work a bit easier for her.

She says: "When I found myself unemployed, I thought 'It's time for a career change!' and decided that I'd like to go into catering or some type of admin work. I know you need a computer to do that, and if I struggle I know Richard will be able to help me with any questions I might have. I know he'll help me do my CV on the computer and put it up online too.

**"In the future, you're not going to be able to do anything unless you do it online. Getting on the internet has given me a bit of an open door. If mum gets poorly and I can't go out, it allows me to have a few hours to myself."**

For Karen and her new friends she's met at the classes, Lincs Training has been a real life-saver. She says: "The classes are within walking or biking distance - that's great for me and the others that are in the same situation; if things do go wrong at home you know you can get back, and if you leave the class halfway through, they don't mind.

"Louth hasn't got anything else like it and it's a real life-line for computer beginners. If you don't know very much about them, having somebody there who knows what they're talking about and can explain things to you in plain English is great. They're so understanding and patient, and I really couldn't ask for two better teachers than Rich and Tony!"

## Finding 6. Digital exclusion is a key issue amongst carers

**12.6 million UK adults lack basic digital skills<sup>30</sup> and 5.9m people have never been online<sup>31</sup>. 19% of carers think they would benefit from support with using computers and the internet and 20% are undecided.**

- **26% of carers don't go online anywhere other than their home, on any device.**
- **Of those who feel they would benefit from support, 44% want to feel more confident using computers and the internet.**
- **Of those with concerns over using the internet, their biggest worries are internet safety, their own anonymity and the internet's impersonal nature.**
- **While many carers are using the internet to make their lives easier, many still don't understand the benefits the internet can bring. Some are using forums but many carers are not.**
- **Our surveys revealed that 48% of carers are finding health information online, but there is little use of the internet to manage their own health and wellbeing (11%).**
- **Carers would prefer to get support with computers and the internet at home, from a family member, friend or community organisation.**

There isn't any specific data on the number of carers who are offline or who lack basic digital skills, yet we know that age, disability and socio-economic status are big contributing factors to the likelihood of someone being digitally included. In terms of age, people without basic digital skills are most likely to be aged over 65 (57%), and in terms of socio-economic status, 69% of people who lack basic digital skills are from C2DE households<sup>32</sup>. Furthermore, 27% of disabled people have never used the internet, compared to 86% of the UK population<sup>33</sup>. Many carers fall into these disadvantaged categories - we know that 46% of carers are not in work and not looking for work, the likelihood of caring increases with age, and 15% of carers have a condition that limits basic physical activity.

There are various reasons why some carers are digitally excluded - they may face barriers relating to access, skills and/or motivation. Our research revealed that carers are concerned about the lack of affordable internet access available to them. Many carers aren't in work, and many face financial difficulties, so it's understandable that a large proportion aren't online at home (one Research Partner estimated that 40% of their carers aren't online at home). Cost, internet safety and worrying about if and when something goes wrong are the biggest barriers to carers getting home access. Issues around internet connectivity can also be barriers, particularly in more rural areas - which is the case for 3 of the Carer Research Partners involved in this project.

For many, the caring role means they are more restricted to when they can get out of the house. It isn't surprising then that 26% of carers don't go online anywhere other than their home at all on any device (this rises to 65% for carers ages 65+). And it would seem that digital confidence has a big part to play in this, meaning that many carers are missing out on

<sup>30</sup> Ipsos MORI (2015) [Go ON UK Basic Digital Skills, UK report 2015](#)

<sup>31</sup> ONS (2015) [Internet Users 2015](#)

<sup>32</sup> BBC (2014) [BBC Basic Online Skills May 2014, updated November 2014](#)

<sup>33</sup> ONS (2015) [Internet Users 2015](#)



the benefits of internet on the go. For those that say they aren't confident with computers and the internet, the number not going online anywhere other than their home, on any device, more than doubles from 26% to 55%.

33% of carers have concerns around using the internet. Of these:

- **44% are concerned about internet safety, including ensuring dependents are safe online.**
- **12% are concerned about lack of anonymity.**
- **11% are concerned about the impersonal nature of the internet.**

With everything else that's going on in their lives, digital is understandably not high on the list of priorities for carers, leaving some unaware of its potential benefits. While online shopping and online communication is common, only 15% of survey respondents use the internet to claim benefits online, 31% to save money online and 11% to manage their own health and wellbeing. From our research, those carers who said they lack digital confidence are also less likely to shop online (61% versus 81% of all carers) keep in touch with friends and family (52% versus 74%), bank online (31% versus 69%) and find health information (29% versus 48%).

*"It's one more thing for me to be messing about with when really I just need to feel as though I am functioning as a normal member of society - someone who is employable, has a job and can afford to go on scuba diving holidays (I really miss them!)"*

**Carer, aged 35-44, caring for child and sibling under 18 years old**

97% of carers don't currently get any support with computers and the internet, yet 19% feel they would benefit from some support. The less digitally confident say they would benefit even more (38% versus 19% of all survey responders). Those that do currently get support are mostly getting it from family (80%) Many of those that aren't currently getting support say there isn't anything stopping them, but in general it's a lack of time, uncertainty about where help is available, not feeling entitled, thinking it's going to be too expensive and feeling resigned to the fact they have to do everything on their own that are the biggest barriers.

*"This would be amazing and it's on my to do list - however as I am a single parent things take time and I don't know where to go for support. Instead I have to research and then find support that I can access - a long process."*

**Carer, aged 35-44, cares for child under 18 years old**

50% of carers who feel they would benefit from support would prefer to be supported at home, 46% by family, 43% at a community organisation, and 37% by friends, rather than at a library (17%) or college (14%).

- **44% want to feel more confident using computers and the internet in general.**
- **44% want to communicate with people in a similar situation to themselves.**
- **41% want to learn how to find general information online.**
- **40% want to learn how to find information specific to their caring duties.**

## 5. Recommendations

With national organisations such as Carers Trust, Carers UK and Family Fund already doing fantastic work to support carers, plus 39% of the UK online centres network supporting unpaid carers<sup>34</sup>, here are our recommendations for how digital and community support can be developed to support carers more.

### 1. Unpaid caring is a hidden issue. Tinder Foundation and partners need to work together to raise the profile of caring

#### How can digital help?

- **Awareness raising:** Embed videos and case study stories into well-used websites like NHS Choices and condition-specific websites like Alzheimer's Society and The National Autistic Society to trigger carers to think of themselves as such and connect with support on offer. Target younger carers through websites like Facebook.
- **eLearning:** In the form of advocacy support and examples of what carers can say to health professionals to ensure they are being heard.
- **Easy communication channels:** Facilitate easy online communication between carers and health professionals.
- **Local signposting and tailored information:** Bring together online recommendations for safe and accessible places carers can use with people they care for.

#### How can organisations help?

- **Profile raising:** National organisations including non-carer specific organisations like Tinder Foundation can help raise the profile of carers within their networks and continue highlighting the barriers facing carers and the tireless work they do.
- **Identify and signpost carers:** Reach unpaid carers (particularly those who don't identify as such) with a message they identify with, showing support available, for example through outreach in GPs and pharmacies - places where people go day-to-day.
- **Facilitate peer support:** Connect carers for confidence building, encouragement, self-esteem support and intergenerational learning. In particular younger carers can learn from the experiences of older carers.
- **Training with a local reach:** Local organisations can provide training and advocacy support to carers on how to be assertive with health and other professionals.
- **Awareness raising amongst local health partnerships:** Ensure GPs and other health professionals understand the importance of signposting carers to local carer support services and to make asking carers how they are a matter of course.

*"[Things that could help are] a site that showed local support and allowed you to contact them online. An advocacy system that could contact people and get them to communicate by email/online chat."*

**Single dad aged 35-44, with a learning disability, looking after disabled child under 18**

<sup>34</sup> Taken from UK online centres Q3 Quarterly survey 2014-15

## 2. Carers lack time. Tinder Foundation and partners need to work together to support carers to save time and focus on their own health

### How can digital help?

- **Digital skills:** Online learning can help carers to develop digital skills, showing how the internet can save them time and help make their lives easier, for example through online shopping and banking, booking appointments online, managing and saving money, connecting socially, improving their health and facilitating easier contact with government services. Much of this content already exists on Learn My Way<sup>35</sup> and could also be added to partner organisations' websites, to reach more carers.
- **Trusted connections:** The internet could help link up carers with suitable respite cover that is trusted and easy to arrange, to give them the break they need.
- **Health and wellbeing resource curation:** Bringing together useful health and wellbeing tools recommended by carers, including websites like NHS Choices, MIND's Elefriends, Facebook support groups and online carer forums<sup>36</sup>.
- **Administration tools:** Develop and/or recommend tools that could help carers with administration, keeping organised and knowing when appointments are.
- **eLearning:** Offer support strategies to enable carers to look after their other dependents.

### How can organisations help?

- **Training with a local reach:** Training for grassroots community partners on providing carers with emotional support and encouraging carers to make space for and to consider their own health and wellbeing. Any support must be flexible as carers may need to reorganise appointments or cancel at the last minute.
- **Awareness raising amongst local health partnerships:** Ensure local organisations<sup>37</sup> know where to signpost carers to for health and wellbeing support.

*"Maybe there could be an online mental health professional doing live chat messaging as sometimes people want to talk but find verbal communication difficult."*

**Mum, aged 35-44, caring for 3 children**

<sup>35</sup> Learn My Way ([www.learnmyway.com](http://www.learnmyway.com)) is an online learning platform, built by Tinder Foundation, especially to make getting online easy. Learners can try the free online courses at home, work their way through with a friend or family member, or go to their local UK online centre for some help and guidance.

<sup>36</sup> In terms of where carers would feel most comfortable getting health and wellbeing support, the percentage relating to online websites and resources is the only one to increase from how carers are currently getting health and wellbeing support (from 11% to 17%)

<sup>37</sup> Carers are going to GPs, local carer groups, charities (sometimes set up in support of a particular health condition), teachers, counsellors and support groups for help and advice.

### 3. Carers are feeling they are missing out on a life of their own. Tinder Foundation and partners need to work together to **empower carers to take control of their lives**

#### How can digital help?

- **Carers Portal:** Having a single online portal for carers, bringing together guidance from Carers Trust, Carers UK, Family Fund and others, thereby ensuring carers are aware of entitlements, e.g. Carer's Allowance, digital tools for fun, learning (such as learning a musical instrument, learn a language, TED talks) and keeping in touch with friends and family.
- **Social networking and online forums:** Creating conditions for connecting carers who have shared experiences, so carers don't feel so isolated.
- **eLearning:** For maintenance and development of carer skills to keep them motivated and ready for work. Provide flexible and distance learning in the form of brain training games like Lumosity, maths and english skills, Open University, OpenLearn and FutureLearn learning.
- **Digital skills:** Provide support for carers to set up their own online support groups, for example through Facebook.

#### How can organisations help?

- **Training and awareness raising with a local reach:** Training for grassroots community partners to support carers in the following ways:
  - Develop flexible employment options, including working from home.<sup>38</sup>
  - Provide guidance on self-employment and how to run a digital business.
  - Provide career advice, planning and skill development and support, including valuing and harnessing skills developed through caring such as organisational and administrative skills.
  - Talk to carers about their own aspirations and provide informal learning opportunities.
  - Support carers to consider future care of those they care for.
- **Offer carers flexible volunteering opportunities:** To build up carers' confidence, allow them to gain experience, develop skills and give them a sense of achievement through voluntary work and sharing experiences with other carers.
- **Embed digital into social events:** Local organisations need to think about the interests and hobbies of the people they're trying to reach and base activities around ways of engaging with these interests online. For example sharing memories with digital photography and online games using tablets.

*"I think maybe it would help to have something to connect like minded people or just a system to help to make it easier to make more friends, both online and offline."*

**Mum 25-34, caring for disabled children and sibling under 18**

<sup>38</sup> 20% of online carers say that using the internet to work from home has had a positive impact on their caring role. Taken from Carers Trust (2011) [How the web can help carers](#)

**4. Carers feel unsupported. Tinder Foundation and partners need to work together to provide tailored support that fits around carer demands and is available when they need it**

**How can digital help?**

- **Local signposting and tailored information:** Having a single online portal (like [Carers Hub Lambeth](#)) featuring local and relevant information which would include trusted, recommended websites and local services from other carers and signposting to local carer groups on specific health conditions. To include age-specific messaging.
- **eLearning:** To keep carers up-to-date on carer best practice, practical advice and condition-specific expertise.
- **Accessible peer and emotional support:** Online tools to match carers with befrienders/mentors for 1-to-1 motivational and non-judgemental support.
- **Digital skills:** Supporting carers to search the internet safely, to find what they need.

**How can organisations help?**

- **Training and awareness raising with a local reach:** Training for grassroots community partners to support carers to run their own support groups and involve the wider family in discussions about carer support.
- **Work in partnership:** Work with other local organisations to ensure support is tailored to carers' individual needs and fits in with carer time pressures and demands.

*"I feel that all the information is out there but not all in the one place so maybe help for how to get round the web would help"*

**Carer aged over 65, looking after his wife**

**5. Carers are benefitting from digital technology and local support. Tinder Foundation and partners need to work together to create the conditions for blended support**

**How can organisations help?**

- **Join the UK online centres Carers Specialist Network:** Encourage Carers Trust Network Partners and other local carer organisations to become UK online centres or to be matched with local UK online centres to deliver digital skills training in a blended support package (combining face-to-face and digital support), including at outreach locations<sup>39</sup>. Where possible, offer options to support carers with digital skills development in their homes, in particular PC maintenance and internet security.

<sup>39</sup> The UK online centres network is the biggest digital inclusion network in the country. It brings together more than 5,000 organisations and 25,000 volunteers working in their communities to help people develop their digital skills. Benefits include access to an online learning platform, management data, forums, training and inclusion in national campaigns (<https://www.ukonlinecentres.com/join-the-network>)

- **Digital skills training:** Support carers to use online resources to help them manage their health and wellbeing, including carers' forums, by raising awareness of them and supporting carers to stay safe online and get used to sharing<sup>40</sup>. Organisations may require training in order to support carers in the best possible way.
  - **Digital Champion training:** Training carers and care professionals to become Digital Champions so they have the confidence and skills to support (other) carers to get the most out of digital technology.
- 6. Digital exclusion is a key issue for carers. Tinder Foundation and partners need to work together to get more carers online.**

### How can digital help?

- **Access:** Online tools such as the Tinder Foundation [Home Access Diagnostic tool](#) can help carers find the best and most affordable device and connection for their needs. Broadband maps like the [uSwitch Broadband postcode checker](#) are useful to ensure users are aware of connectivity options before they commit.
- **Motivation:** Video resources and embedding case studies into Carers UK, Carers Trust, Family Fund, NHS Choices and condition-specific websites, showing how carers have benefitted from the internet, can be a good source of motivation.
- **Digital skills:** eLearning platforms to develop carer digital skills to interact safely online and be sure of anonymity online e.g. Learn My Way, BBC Webwise and Youtube. Embed these platforms in partner and well-used websites mentioned above.

### How can organisations help?

- **Digital Skills and Access Audit:** National organisations need to pinpoint where the need for digital training and access currently exists within their networks.
- **Access:** Local carer support organisations must consider offering carers access to the internet as part of the services they provide and to raise awareness of affordable access options amongst carers, such as pay as you go, MiFi and dongles.
- **Mobile tech:** Sell the benefits of mobile technology to carers such as information and entertainment when out and about e.g. whilst waiting for a GP appointment.
- **National lobbying:** National organisations to lobby internet providers to reduce the cost of devices and internet connectivity for carers.

*"[It would be useful to have an] online course that helps develop computer skills and qualifications to allow return to the work place sometime in the future."*

**Carer, aged 45-54, looking after family member aged under 18**

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<sup>40</sup> Tinder Foundation are working with The University of Sheffield on their research project '[A Shared Space and a Space for Sharing](#)', an ongoing study into how and why people choose to use online forums to find and share information that helps them deal with difficult circumstances, including long-term health conditions (See Tinder Foundation's November 2015 Blog '[Online Health Forums and Digital Exclusion](#)')

## 6. Conclusions

Caring has a huge impact on carers' health and wellbeing, the impact of which is felt very differently by each person in a caring role. Tiredness, social isolation, worrying about the future and not feeling relaxed are just some of these impacts.

Tinder Foundation's research with Carers UK, Carers Trust and Family Fund has revealed a number of challenges facing carers - from receiving the support they need, to helping them maintain skills and social networks. With 70% of carers caring more than 50 hours a week, carers lack time to seek support, and even when they do feel on top of things, they struggle to prioritise their own health and wellbeing when those they are caring for are their main focus. Carers say they don't know where to look for the support they need, and the support that does exist doesn't always fit in with the demands of their caring duties.

Digital can be an important tool to help carers save time, bring information together in one place and offer flexible and tailored support when carers need it - night and day. However many carers are digitally excluded and aren't able to benefit from digital tools because of lack of access, skills and/or motivation. That's why Tinder Foundation, alongside national and local partners, need to continue to work together to help digitally excluded carers overcome these barriers by addressing issues identified in this report, lobbying for, co-producing and delivering future digital support.

Trusted, local support from community organisations such as UK online centres (including through the outreach that they do), Carers Trust Network Partners and Carers UK affiliated organisations, plus home visits from Family Fund, are not only vital to the health and wellbeing of carers, but are also key to delivering current and future digital skills support in friendly, safe environments, which carers are more likely to stay engaged with and benefit from.

Furthermore, there is work to be done around awareness raising and suitable messaging to carers at a local level to ensure they can benefit from the online and offline support already available. Community organisations are perfectly placed to do this, and can translate information produced at a national level, using their unique reach to help carers understand the support that is available to them in their own communities.



## Appendix 1:

### Project Partnership

#### National Partners

##### Tinder Foundation

Tinder Foundation is a not-for-profit social enterprise that makes good things happen with digital technology. Established in December 2011 as a staff-owned mutual, our 40-strong team supports a network of 5,000 local community partners and works with hundreds of national organisations. Through the network Tinder Foundation supports thousands of community partners to be smarter in how they use digital technology, including through our [Community How To website](#) and the [Learn My Way online learning platform](#), which has helped more than 1.6 million people gain the skills they need to use computers and the internet confidently. 39% of the network support carers with basic digital skills or other support. Tinder Foundation receives funding from a mixture of public, private and third sectors, including from the Department for Business, Innovation and Skills, NHS England, TalkTalk and EE.

***“Tinder Foundation manage a network of local centres across the country, including the Carers Specialist Network, which focus on supporting carers with digital inclusion learning and wider support including financial management, employability skills and health support. ”***

##### Carers Trust

Carers Trust is a major new charity for, with and about carers. It works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

It does this with a UK wide network of quality assured independent partners, through unique online services and through the provision of grants to help carers get the extra help they need to live their own lives. With locally based Network Partners it is able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. It offers specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

[Carers.org](#), [babble.carers.org](#) and [matter.carers.org](#) are UK wide help and support services, provided directly to carers every day of the year using the latest technology platforms. Staffed by a team of qualified social, youth and community workers, they support carers of all ages with fast, age-appropriate and confidential support. This is provided through email helplines that are monitored daily (including Sundays and public holidays) and answered within 24 hours; supervised and moderated message boards available 24 hours a day which give carers the chance to discuss, comment, chat with and support one another; and live chatrooms where carers can interact with staff, other carers and with a variety of guest experts on subjects that matter to them.

***“We make sure carers voices are heard and that we listen to what they have to say. The vast majority of emails we receive are from carers who have no contact with a support service, so we point them in the right direction. Digital inclusion is important because people need to find us, otherwise they are excluded from useful resources.”***

In terms of Digital Inclusion, Carers Trust are currently exploring a project ‘Get:Connected’<sup>41</sup> which aims to match up younger and technologically confident carers with older less confident carers with life and caring experience, for a skills exchange.

## **Carers UK**

Carers UK is a charity with 50 years’ experience of working to improve the lives of the millions of people who care for family members and friends. The organisation has a membership of 20,000 carers and a network of 350 affiliated organisations. As well as working with the government to advise on policy for carers and lobbying and campaigning on behalf of carers, Carers UK also directly supports carers through their website, online forum (which has 3,000 users), online campaigns and online Q&A sessions e.g. through Facebook. Carers UK also has virtual carer networks for employers and a suite of e-Learning and online products to support carers and service providers such as local authorities and care providers.

***“Carers are more likely to trust other carers who have an understanding of what it feels like. But sometimes they want expert advice from skilled people, or just for listening. Our forum can be used for both - to share or get advice. Our focus all the time is to reach carers as early as possible to ensure they get the support they need.”***

Over 6.5 million people in the UK are currently caring and while caring is part and parcel of life, without the right support the personal costs can be high. Carers UK is committed to identifying and promoting new solutions to support carers, including through use of technology.

## **Family Fund**

Family Fund is the UK’s largest charity providing grants for families raising disabled or seriously ill children, helping 72,043 families last year with over £33 million of grants and services. They are funded by the four UK governments, private donations and income generated through the work of their trading arm, Family Fund Trading. Family Fund provides grants for a wide range of items, such as washing machines, sensory toys, family breaks, bedding, tablets, furniture, outdoor play equipment, clothing and computers. As part of their assessment process, they visit over 11,000 families a year.

***“Health and wellbeing doesn’t mean much to carers and many of the parents we support don’t see themselves as carers. Having conversations are important and for some families, our visit might be the first time they’ve told their story - there is a lot of value in that. You get a window into people’s lives.”***

Family Fund believe that all families raising disabled and seriously ill children should have the same opportunities as others. It can be a struggle financially, emotionally and physically for families raising a disabled or seriously ill child, and these grants help break down many of the barriers families face, improving their quality of life and easing the additional daily pressures.

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<sup>41</sup> Get:Connected is not yet an active project. Carers Trust are currently seeking funding to develop it.

## Community Partners

### North Bradley Peace Memorial Hall

Pauline Baxter cares for two people as well as having a part-time job and is a Volunteer Coordinator running a weekly computer club in North Bradley Peace Memorial Hall in rural Wiltshire. The Computer Club sees up to 12 carers each week, ranging in ages from 30's to 90's, who use the laptops with the help of Pauline, volunteers and each other. The sessions aren't just for carers but Pauline has found that conversation during the class often reveals learners' caring responsibilities. As a carer herself, Pauline is able to relate to the learners and uses her own experience to encourage and motivate them to have a go with the online world. Sessions are very relaxed, with tea and biscuits provided. Volunteers normally sit down with carers to support them with the practical sides of things once they've gone through Learn My Way. They would love to put on more sessions but volunteer time and finances are limited.



NORTH BRADLEY  
COMPUTER CLUB

***"I think it's an invaluable service, even if it's just one person turning up. I provide a listening ear and point them in the right direction to find information about caring (if they want it). It varies - some people come wanting a distraction from caring and some want to find out every single detail about the illness of the person they're caring for online. The main thing is that we are a non-judgemental bunch."***

### Liverpool Carers Centre (a Carers Trust Network Partner)

Liverpool Carers Centre (LCC) sits under the umbrella organisation of Local Solutions, which engages vulnerable people. LCC conducts initial assessments for carers' needs, resulting in referrals for either [More Independent](#) (life-enhancing technologies to help carers live more independently) or digital inclusion classes. Megan, the More Independent Carers Pathways Coordinator, runs three digital inclusion classes a week, with support from volunteers. Classes are also delivered in local job centres and GP morning sessions and mainly comprise supporting learners through Learn My Way, but there are also progression routes for more advanced users.



  
**Local Solutions**  
Engaging, Enabling, Enhancing

The popularity of classes means that there's a waiting list to start and the enthusiasm of learners means that they often want to attend classes for longer than the initial 6 week course.

***“Digital hubs is one of the most attended activities in the centres so the importance is understood across the organisation. We don't have difficulty engaging with carers, but if we were to offer a wider range of activities we'd be able to have more people engaging. It's all down to resources and volunteers.”***

## Lincs Training

Rich Avison is Centre Manager at Lincs Training, delivering digital inclusion sessions in outreach locations across rural Lincolnshire, including [Trinity Centre](#). As a carer himself, Rich says he got to know many carers and was able to show them how computers and the internet could make their lives easier. Soon they were telling friends and fellow carers.



Trinity Centre was chosen as a good location for computer classes because of good broadband and the presence of other established support services such as Alzheimer's Society, housing, credit, dementia and money management groups. Rich also does a lot of work with Lincolnshire Carers Partnership and gets referrals from the Local Authority housing team for money management and health information online.

Lincs Training focus the majority of their digital inclusion activity on Learn My Way, taking learners through all the courses. Rich is currently developing some courses for Learn My Way, specifically for carers. He finds one of the main challenges supporting carers is that they aren't always available to attend sessions. Rich doesn't have the capacity to support everyone in their own homes, so he hopes that the online courses he is developing will mean more carers can choose when and how they learn.

***“We're here to help. Computers and the interest is the key thing that brings people in. But it's not an overnight thing, trust builds up over time”.***



## North Lincolnshire Carers Support Centre (a Carers Trust Network Partner)

North Lincolnshire Carers Support Centre (CSC) are commissioned by the North Lincolnshire Council to provide support services to carers. They have been running for over 25 years, becoming a UK online centre in 2014. The services they offer include home care system, lifelong learning, advocacy, advice, signposting and counselling. They also run a befriending service for carers who might be lonely or isolated.



CSC have been delivering computer classes and providing free internet access to carers for years as part of their Lifelong Learning project - giving carers a break from their day to day responsibilities and to help broaden their horizons. Volunteers (many former carers) are key to making sure that each carer gets one-to-one computer tuition. Because volunteering can be a big commitment, Lifelong Learning Officer Chris Spencer really lacks volunteers and computer tutors due to other responsibilities. This has a big impact on carer progression as only with regular and continual support can the trust build up.



Chris says that on top of the everyday challenges facing carers, the rural nature of North Lincs brings extra challenges with poor public transport provision and services being spread out.

***“There is a push to get people online but people can't get online when they absolutely need to access the support. A lot of carers don't see the internet as a priority as they want to save money on other things. But this impacts them as they could save money online anyway.”***

## City and Hackney MIND

City and Hackney MIND are the fifth largest MIND in the country who in 2014 won a major contract with Hackney Borough Council to manage mental health delivery in the borough and to subcontract to other services. Their single point of entry approach to the project focuses on prevention, recovery and wellbeing, helping build resilience of individuals, aiming to reach people before crisis point - something they are finding requires a huge cultural change amongst service providers and users. An important part of their work is to support people with mental health issues to get



back into employment, including supporting welfare rights and tribunals, providing benefits advice and helping people with appeals. City and Hackney have recently launched a new service called 'Hackney Connect', specifically to help identify carers. They already give Carers Assessments to those identified as being in need, through which they promote support available to carers, including therapeutic interventions and computer classes. They support carers of a variety of ages, but struggle to engage with younger carers because of the stigma attached to mental health. Through their Wellbeing Network they are able to offer a variety of health and wellbeing support including hobby and interest led sessions and employment training. Anne Thomas, Head of Employability, believes there is much potential for carers to use the internet to find information in the local area. City & Hackney MIND offer digital skills sessions to carers as part of their wider offer to people in the local area.

***“We are 100% well placed to support people with health and wellbeing. We listen and design support around what people want from a ‘menu’ of what’s available. Our new Wellbeing Network means we can do more evening and weekend courses”***

### **Age UK Hereford and Localities**

Age UK supports people aged 50 to 90+ and their families to live well in later life, and intertwines mental health and wellbeing throughout everything they do. Carers are a big part of their client group - whether as a result of them identifying themselves as such or being identified through conversations with Age UK advisers.



Sarah Jenkins is an Information and Advice Manager who alongside five volunteers, works closely with Herefordshire Social Support to identify cases of need and provide information and advice to older people and their families. Age UK also actively tries to reach carers through Carers Groups, events, local GP surgeries and village halls. As a service they recognise that many older people are missing out on certain benefits the digital world brings, and believe digital can supplement face-to-face contact and emotional support.



***“We’re keen to have more support to help us to identify how many carers we see are currently offline, and how many of which would benefit from having internet access.”***

## Appendix 2: Geographic distribution of Research Partners



1. Liverpool Carers Centre
2. North Lincolnshire Carers Centre
3. Lincs Training
4. City and Hackney MIND
5. North Bradley Peace Memorial Hall
6. Age UK Hereford and Localities

## Appendix 3: Timetable of Research Activities

Month	Project Stage
March - April 2015	<u>Engagement, planning and scoping with partners</u> <ul style="list-style-type: none"> <li>• Engagement of Research Partners</li> <li>• Design of research scope and data collection methods with partners</li> </ul>
May - June 2015	<u>Data collection</u> <ul style="list-style-type: none"> <li>• <b>Partners:</b> Semi-structured interviews with national partner contacts and managers at 6 UK online centres</li> <li>• <b>Unpaid carers:</b> Focus groups and demographic surveys with at least 5 learners at each of the 6 UK online centres</li> <li>• National survey administered through National Partner Networks</li> </ul>
June 2015	<u>Exchange</u> <ul style="list-style-type: none"> <li>• Webinar with centre managers and national partner contacts to share and discuss emerging findings, recommendations and actions.</li> <li>• Sharing of emerging findings during Carers Week</li> </ul>
July - October 2015	<u>Data analysis</u> <ul style="list-style-type: none"> <li>• Analysis of research data collected and writing of final report</li> </ul>
November-December 2015	<u>Report dissemination and next steps</u> <ul style="list-style-type: none"> <li>• Report dissemination</li> <li>• Discussions on next steps</li> </ul>



## Appendix 4: Acknowledgements

### National Research Partners

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- **Clare Kassa, Andy Simpson and Jim Paterson, Family Fund**
- **Michele Lambert, Ewan Main and Sam Symington, Carers Trust**

### Community Research Partners

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- **Rich Avison, Lincs Training**
- **Chris Spencer, North Lincolnshire Carers Support Centre**
- **Megan Evans, Liverpool Carers Centre**
- **Anne Thomas, City and Hackney MIND**
- **Sarah Jenkins, Age UK Hereford and Localities**
- **Pauline Baxter, North Bradley Peace Memorial Hall**

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Last but not least, a huge thank you to the carers who took part in our focus groups and the 1802 carers who took the time to complete our survey and for sharing their thoughts and experiences so openly.

### Tinder Foundation Project team

Report prepared by Tinder Foundation's Research & Specialist Insight Manager Emily Redmond, with support from Alice Mathers, Fera Baybutt, Anna Osborne, Vicky Lawson, Dora Damian, Holly Bagnall-Bell, Kate Mason, Zoe Harris, Sam Taylor, Kehinde Balogun, Ben Fraser and Sarah Coe.

## Appendix 5: Carers Week Blog Links

- Project Announcement: [National Carers Week: Can the internet help?](#)
- Tinder Foundation: [Carers Week: What are the biggest challenges for carers?](#)
- Madeleine Starr, Carers UK: Carers Week: [Carers UK helping carers find the support they need](#)
- Clare Kassa, Partnership Development Manager, Family Fund: [What it means to be a parent carer](#)
- Tinder Foundation: [Carers Week: What next?](#)