

# Spotlight on a Carer's Journey

*Exploring what works in supporting carers through the care act*

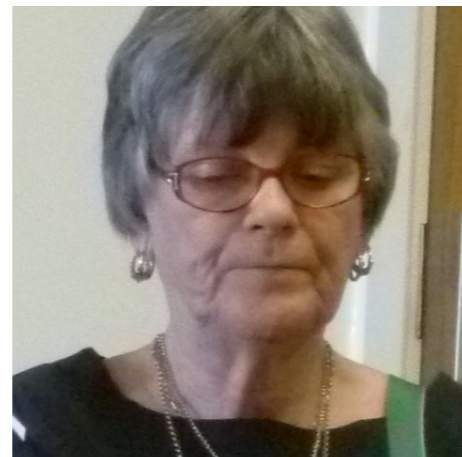
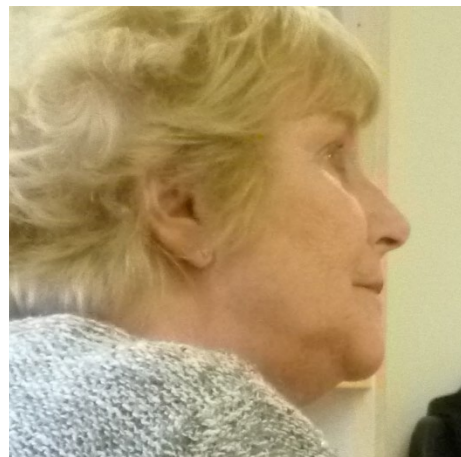
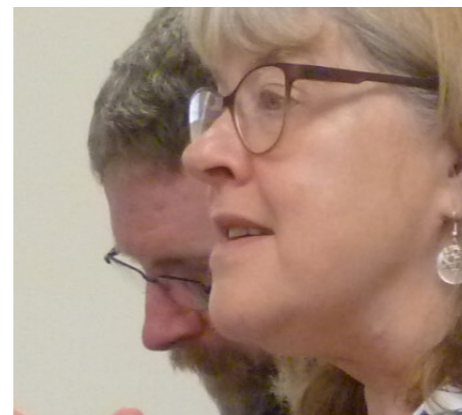


National Development Team for Inclusion

a guide for organisations who  
provide and commission support for carers



The project was set in two differing localities, where Local Authorities, commissioners, local carers organisations, families, friends, carers (the occasional pet), and many others took the time to plan their own local priorities for carers under the Care Act and reflected with us what they had learned as part of their own journey towards implementing the Act in the first year, and most importantly what this meant for real people with real lives.



## Background

In April 2015 the Care Act (2014) went live. For the first time in legislation, carers were put on an equal footing with the person they support - putting an equal value on their needs and the need to promote their wellbeing.

The vision of the Act is to actively promote 'Wellbeing' and quality of life and not just wait and respond when people and their carers reach crisis point. The Care Act was therefore widely welcomed as a major step forward for carers across the country.

This guide is aimed at organisations with a role in providing and commissioning support for carers, including peer support networks.

This publication highlights some of the issues raised by a small project exploring the experience of carers as Local Authorities worked to implement the act in the its first year.

The aim of the project was to focus on;

- Understanding the key elements of the 'Carer Journey'
- Understanding the carers experience within it
- Understanding the role that Personalisation should and can play in promoting Carer wellbeing

inspiring  
positive  
change and  
good  
practice

This work provides an opportunity for a brief exploration into the implementation of the Care Act over its first year. As emphasised in other recent publications, this has not been smooth or without challenge. This document should be read in conjunction with other key publications on carers including the State of Caring (Carer's UK 2016) and the upcoming Carers Strategy (Department of Health).

Given the scale of the challenge, this guide highlights some of the good practice that informs discussion and can inspire change as people continue to grapple with the implementation of the Act.

During the project we found examples of excellent and creative support which is enabling many who care for others to live a good life. With this in mind, this publication aims to share the learning from these experiences and shine a spotlight on what works, with the aim of inspiring positive change and good practice.

## The Carer's Journey



Identify as a carer



Information and advice



Preventative Community Based Support



Assessment eligibility & need



Personal Budget



Person Centered Support Plan



Support to live life well and care

### Journeys are not always linear, and nor do all carers walk this entire pathway.

However the Care Act brings new rights and entitlements to those who care for loved ones in a variety of areas. For those who benefit from all of those entitlements, the sequence is likely to be closely aligned to this Care Act Journey. The key starting point is the realisation that you are a carer followed by the support or experiences which enable this role to be carried out whilst maintaining your own wellbeing. There needs to be a recognition that the 'carers journey' does not come to an abrupt finish when the caring role comes to an end. A carer might well need support to continue to live well through the transition of adjusting to no longer being a carer; a role they may have played over many years and have come to value.

### The idea of wellbeing includes...

- **Personal dignity** (*including treatment of the individual with respect*)
- **Physical and mental health and emotional wellbeing**
- **Protection from abuse and neglect**
- **Control by the individual over day-to-day life** (*including what or how care and support is provided*)
- **Participation in work, education, training or recreation**
- **Social and economic wellbeing**
- **Domestic, family and personal relationships**
- **Suitability of living accommodation**
- **The individual's contribution to society**



## Identifying as a carer

Without identifying as a carer, it is difficult to access the help and support that carers are entitled to under the Care Act.

"But am I a Carer"? This is a theme which emerged again and again from the people we spoke to who were caring for loved ones and family members. One of the contributing factors is that people are looking after family members, partners or close friends. What becomes caring, they see simply as a natural extension of those relationships.

There is a clear role for organisations and support services to identify carers

The term 'carer' itself is still causing issues. Many people feel resistance to the label as they see the support they offer as just what you do in families. To take on a formal label of 'carer' hasn't occurred to them. Of course that means they run the risk of not accessing the information and support they need to help them in their caring role.

There is a clear role for organisations and support services to identify carers, as well as to help people self-identify. This will enable carers to get the best information, advice and support to promote and maintain their wellbeing.



## What works

Carers are everybody's business. Build carer awareness in universal mainstream services as well as health and care.

Develop carer "champions" in teams of health and social care professionals.

Link and embed carer support workers within GP practices and multi-disciplinary teams.

Being embedded in primary care has been key to success in reaching new carers in Bradford. It has enabled GPs, who are often first to realise someone might have a caring role, to help them self-identify and pass them immediately to someone who can help them explore their own needs. Bradford Carers' Resource also link with a number of local multi-disciplinary teams to reach people who may be contacted via their loved ones.

Camden's successful multi-disciplinary team includes not only representatives from across health and social care, but also local third sector carers' support. This approach maximises the outcomes for the individual as they gain the support around them that they need. It also helps families and friends recognise their own needs and the support available to them.

Build flexibility into the local system. Some caring roles might involve intense caring for a few weeks, and then need no input for a number of months. Where things work well, the carer and the person they support get the input they need when they need it, without restrictions on having to spend budgets evenly over a year.

Invest in carers support workers and others who reach out to especially vulnerable groups such as parents with a learning disability.

Perhaps most importantly, is to help carers themselves realise that the roles they are playing may be above and beyond family life and they may warrant their own support, both to stay physically and emotionally well and remain caring.



## Carers' voices

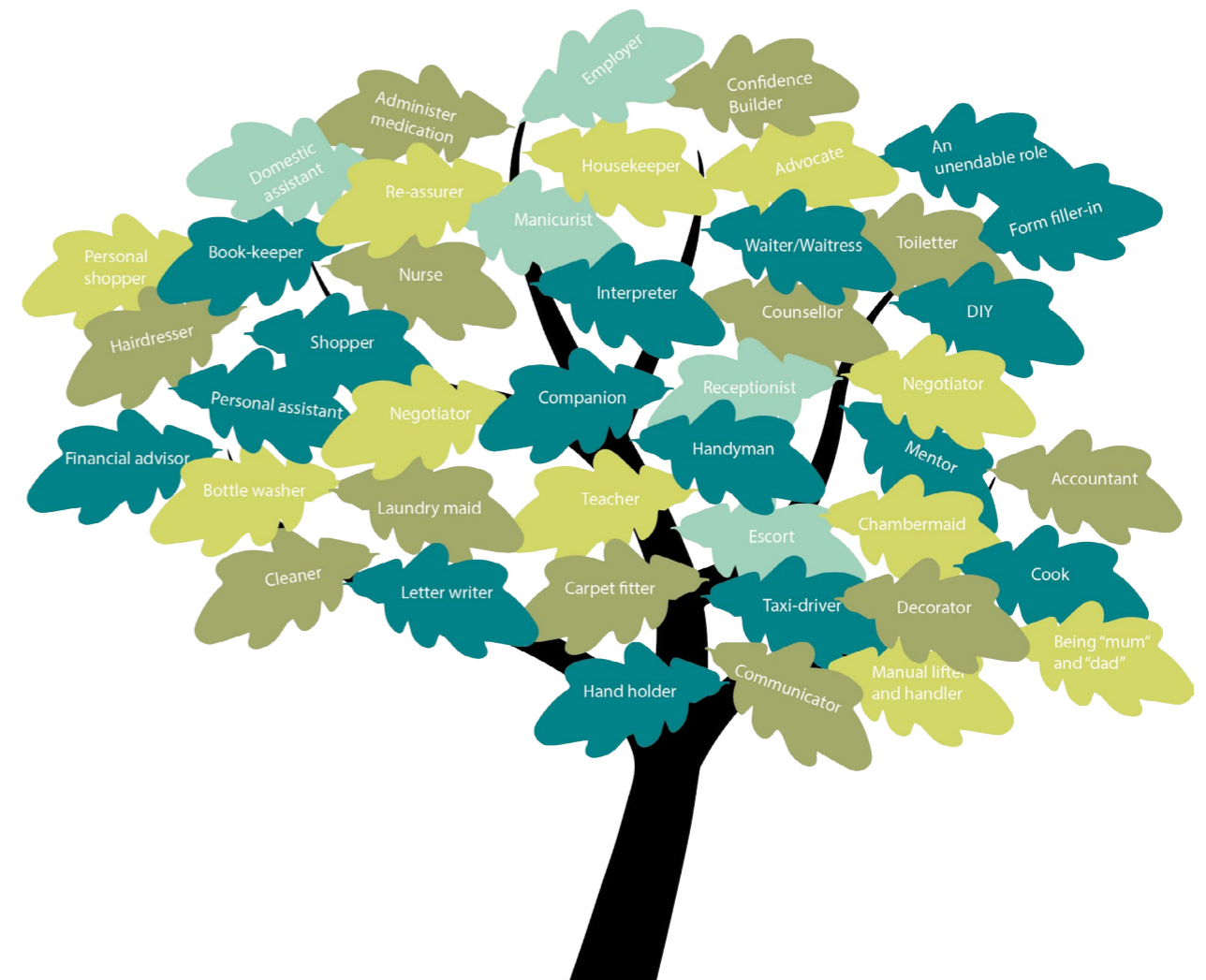
### Marlene's story

"I left my home in Croydon to come back to Yorkshire to look after my mum. I did this for 6 years and never realised I was a carer. 3 years ago when I was getting to a crisis point I was put in touch with Carers' Resource.

"They helped me realise I was a carer and recognised I needed a life too. I joined the group and did things like the art group. It was so helpful to meet others in the same situation as me to be able to talk and I discovered how much I love art.

"I have saved up to go on a course which I am starting now. It means my sister will need to look after mum when I go. She might not know how to make tea just like mum likes it, but I know they'll be ok."

Marlene, Yorkshire



"Carer's Tree" Identifying the many roles of a Carer - Reproduced by kind permission of Carers' Resource



## Information and advice and knowing your legal rights

The most useful information and advice is the right information, at the time in which it is needed, and in a format which makes sense to the person.

Information is vital to empower carers to make informed choices both for themselves and the person they care for.

Carers told us that whilst leaflets and online information can play a valuable role, it has its limitations. What they valued most was being able to speak to someone over the phone or have a face to face meeting with someone who would listen to them and direct them to the information they needed.

**Local authorities have a duty to provide information and advice. What carers want is information which is personalised to them.**

The Care Act places a duty on local authorities to provide information and advice to individuals with support needs and their carers. Carers involved in this work also spoke of the importance of not just knowing what support is available, but also what relevant laws say. Knowing their own rights, and those of their loved ones is key to people being empowered, and to avoid the perennial situation where they feel they are having to “fight the system”.



### What works

Provide a one-stop-shop where information can be reached, at the right time, and be filtered depending on the person’s needs and is available in various formats. Include online information, a phone line and paper information which can be sent out to people.

Have carers support workers who can help carers find and understand what information is needed and relevant to them, including the more unexpected requests.

Co-produce a communication plan with local carers and their supporters in statutory and voluntary services where carers can lead on saying what information they need and want.

Derbyshire county council are working with carers and partners to develop a strategy to reach and provide the right information to carers across the county. This includes finding ways such as workshops and advocacy to help carers know their rights under various relevant legislation.

Run drop in information sessions on different laws. The ones carers were particularly keen to understand in relation to their own rights included the Care Act (2014), The Mental Capacity Act (2005).

Personalise the information and advice provided to carers.

A carers support worker in Thinkcarer who work with those caring for loved ones with mental health support needs, described her “Mary Poppins bag” from which she can draw the right information for whatever the carer she is talking to needs, be it about benefits, finding activities, respite, or keeping fit.

Ensure they have the right information and support to maintain financial security e.g. through benefits advice and support.



### Carers’ voices

The Carers Resource help-line in Shipley received a call from a man who was going into hospital the following day. He had arranged respite for his wife, and found someone to take care of the dog. But he realised he’d forgotten to make plans for the birds in his tropical aviary to be looked after in his absence.

The carer’s advice worker was able to find a local vet who specialised in tropical birds, make contact with them and see if they could contact the man. The vet agreed to help over the next few days, and then found when he visited the birds that he had a friend who lived much closer. He linked up the man and his neighbour and the aviary was maintained as well as the carer’s peace of mind.



## Prevention and community-based support

The Care Act introduces a new duty on local authorities to provide preventative support options. This recognises **if you can help people maintain wellbeing you can help prevent them from needing to use formal services, or for their caring role to break down.**

Good preventative support comes in many guises. From a carers perspective, often the first thing was to get the right support in place for the person they were caring for. However, people talked about their issues of isolation and the importance of peer support.

Building or rebuilding self-esteem and their own life, including learning and working, was essential. We heard of the importance of carers staying well, mentally and physically. People shared examples of relaxation, de-stressing and keeping fit to achieve this. With the right information, advice and support from third sector organisations, many carers are getting support to live well in their own local communities.



### What works

Peer support is invaluable. It offers opportunities for carers to get together which are focused around an enjoyable or interesting activity or topic. Include time for open chat and peer support.

In some areas we heard that funding for groups had been cut, and support was all focused on the individual. People missed their chance to go to an art group or book club with peers, which gave them the space to share and air concerns without judgement.

Give carers support to maintain or gain work, or develop new skills which can help them move towards working.

Offer support to make their own “wellbeing plans” for connecting with and gaining natural support in their own communities.

Offer small grants for carers to put towards something which will help them maintain their wellbeing.



## Carers' voices

People shared that they had used their wellbeing grants of £250 for all number of things. “A weekend away in the country” “flowers every week to brighten the living room and make me feel good” “a massage every month or two”. Small things could make a real difference.

“I can share what I am going through with other family carers. Sometimes if I tell the family they think I am moaning or not coping. I just want to be able to talk with people who understand”.

### Peer support

**Judy's story:** “as someone caring for a son with a learning disability, I feel the need for support from other carers. There was none available so I approached our church and set up a group. Our motto was “we're there to share with those who care”.

### Work

“The world shrinks when out of work; a few hours of work a week has enabled me to get out of the house which is fantastic. I talk to people about everyday things and work on projects which is uplifting. Work has given me confidence and I'm doing much more than I used to do – my self-esteem has improved.” **Family carer in Hertfordshire**

### Mandy's story:

“I first became a carer for my mum when I was 27. In Wales back then I didn't have any support and eventually she passed away. I got married and my partner had health issues and was losing his sight. At one point I became ill and went to my GP. It was the GP who put me in touch with Carers' Resource because they wanted me to go to hospital and I knew I couldn't go. A family friend had to come in and help until I got back home. When I came home I had a visit from a carer support worker. They found out that I didn't go out anywhere and just stayed inside. They noticed I would have a panic attack just going to the door. So they gave me support to help me get out to places on my own. I started going to college and then working two days a week. Just having time to myself and knowing that I am a person helps. I don't get so stressed. This is also because I know where I can get help, even about things likes benefits and money.”

“You need to moan but don't like to moan to your family cos they might think you're not coping”  
*Freda, Yorkshire*

# Assessment



The Care Act gives carers the right to have an assessment, which seeks to identify whether they have support needs, and whether they are eligible for formal support from care services, which may be in the form of a personal budget.

The Care Act allows for carers to be eligible for their own support even where the person they support does not have eligible support needs. Thus the purpose of the assessment is key to ensuring that the rest of a carer's rights to support are upheld.

**One of the biggest challenges is to get carers to recognise the benefit to them of having an assessment.** It's essential that carers understand the process and have a chance to prepare, and the assessment is carried out by someone with the right expertise. Carers UK (state of caring 2016.) found that only 31% of respondents had had a carers assessment.

Of those who had an assessment, Carers UK found only 1/3 of those felt that their support to look after their own physical and mental health had been considered. Many carers are still having to wait for more than 6 months for an assessment.

The purpose of the assessment was sometimes misunderstood by carers and professionals. Its purpose as a process to identify needs, and eligibility for a personal budget and support plan, means this is a key component in the journey to personalised support that the Care Act promises.



## What works

**Ensure that carers are pointed in the direction of the social worker** who can carry out their assessment, for instance by providing a range of sources of information and routes to get an assessment.

**Ensure there is capacity to offer timely assessments to carers.** This may be especially important if their loved one is in crisis or nearing the end of their life. A good prioritisation system could ensure that carers do not have to wait for the assessment and the support that they need. Whilst carers are waiting for an assessment, ensure that they have been provided good information and linked with local community carers organisations who may be able to provide support without an assessment.

**It is important that carers see the benefits of having a carer's assessment.** Not only will they get greater recognition for the key role they play which could lead to personalised support package for themselves. The key to having a good carer's assessment is to be prepared.

This means supporting carers to think about and even write down in advance all the help they provide on a day to day basis, including any prompting they do as well as hands on care!

**Local authorities need the right systems and structures in place** to ensure the assessment generates an output about the eligible needs the carer has, and the associated costs or budget available to meet the needs. The assessment should not lead straight to support provision before the carer has the opportunity to think through what outcomes they want to focus on and what good support might look like for them, during a support planning process.

**Ensure that the assessment process is focused on the wellbeing principle as outlined in the Care Act.** This means considering factors such as maintaining or gaining employment, maintaining relationships with friends and family and emotional and physical health of the carer are taken into account as well as their ability to continue to care for their loved one.



## Carers' voices

"I have had two carer's assessments by two different departments. One for each son: one resulted in no outcomes, (my son who has greater care and support needs), and the other resulted in a carers personal budget! I employ a cleaner for two hours a week!!" **Wendy, Essex**

Norman had been having support for caring in the form of respite for a number of years. He called to advise of a change in circumstance in May 2015 and was invited to have the new carer's assessment.

He had an assessment many years ago but he had found the format discouraging: "It was more about the person I was caring for, than what I needed to enable me to continue caring. The new assessment is much more inclusive; more about the carers needs and focussed on how I was going to cope with caring. It was so much more supportive, focusing on 'what can we do to help you' rather than 'why can't you manage?'" **Norman, Hertfordshire**



## Personal budgets

Under the Care Act, a carer with eligible support needs is entitled to a carer's personal budget. This is a sum of money paid by a council's adult social care department to help a carer to pay for things which will help them in their caring role.

It allows family carers to have more control over how they are supported. To get a personal budget you will have to have had a carers assessment and the amount received will vary depending on individual situations and support needs.

*Further information can be found here:*

[www.peoplefirstinfo.org.uk/looking-after-someone/support-to-look-after-someone/carer-personal-budgets.aspx](http://www.peoplefirstinfo.org.uk/looking-after-someone/support-to-look-after-someone/carer-personal-budgets.aspx)



## What works

Some areas, including Bradford are using a tiered system whereby small grants can be applied for via a carer's support organisation for basic wellbeing needs without, or prior to, assessment.

The carers centre workers can then signpost those with more significant support needs to social work teams for assessment to see if they have eligible needs and can get a more substantial or tailored personal budget.

Local areas have different ways of identifying amounts. This may be through working purely from the starting point of what is needed and costing that up. In other cases such as Hertfordshire, a simple resource allocation system can offer different bands of budgets at certain fixed amounts.

The flexibility of how people can spend their budget, and the planning which takes place is key to the budget delivering positive outcomes.

Many areas still offer non-means-tested support for carers personal budgets which is extremely helpful, especially in a financial climate in which personal budgets for those needing care and support has seen reductions or increased contributions from the individual.



## Carers' voices

Heather has cared for her husband since he had a flying accident and head injury a number of years ago. Personal budgets have made all the difference to how they have been able to remain together as a family.

"I've had money towards holidays with Phil, instead of respite care. I couldn't afford to save up out of benefit money to go on holidays. The support has helped us to do things that normal families do, which has been absolutely wonderful.

"Over the years carers have been more and more recognised in our own right and last year the carers assessment was changed – we are now officially recognised in the Care Act. We have our own rights as carers." **Heather, Hertfordshire**

Richard has cared for his wife, who has Multiple Sclerosis, for 20 years. He receives a personal budget and has had a lift installed in the family home as a result of his carers assessment.

"The support has been unbelievable, superb. Having the lift has changed our lives." He added about the Direct Payments: "We haven't been able to go out to a restaurant in years. The direct payments mean we have been able to save a little bit of money to be able to treat ourselves. It is so nice to be able to go out together for a nice meal and not have to worry about the money." **Richard, Hertfordshire**





## Person centred (and family centred) support plans

If a carer is eligible and receives a personal budget, they will be supported to create a support plan which will agree how the support will be arranged, and how the budget will be used. Support plans should focus on ensuring that a carer's wider wellbeing is considered as well as the support they need to continue in their caring role.

The support plan works well when it takes into account the wider family network, and at least the person who the carer is supporting and themselves.



## What works

Support plans which work well are developed in partnership with carers and perhaps their families, and based on person-centred conversations. Local areas can ensure that those working with carers are skilled in using person-centred practice, and helping people identify the outcomes which matter to them in their lives.

Support planners should have a good understanding of the opportunities in the local communities in which people live, so they can ensure tailored plans make the most of the locality and non-service based support.

Ensure the care and support plan and budget enable replacement or respite care to be provided where needed.

Building contingency plans into the support plan, which identifies how the loved one can be supported if the carer is temporarily unable to provides extra peace of mind to everyone.

Regular reviews with carers about how the plan is working for them and the person they support will enable changes to be made if something isn't working for any of the family.



## Carers' voices

"I've been able to get my fitness programme paid for weekly with a direct payment. I go to a 'dancefit' class in Hitchin, with my daughter – which is really important family time as well as time for my own fitness. I also have a fortnightly gardener as it is just impossible to stay on top of everything and meet Phil's needs. I still get money for a holiday and I also get money towards social outings; we love going to the theatre and some of the money goes towards that. It can just make all the difference, if the carer's confident and relaxed then the person being cared for is as well – it's a win-win situation." **Heather, Hertfordshire**

Heather argues, however, that the main benefit from having an assessment and support plan is not financial.

"One of the most important elements of the support package is the contingency plan that I have in place. I know if anything happens to me Phil will be looked after – it's peace of mind for the carer that you have put as much as possible in place to look after the person you care for." **(Heather- Hertfordshire)**

"Before receiving the direct payments I couldn't go out unless I got a friend to sit with my husband, they have made such a tremendous difference, I've been able to go back to choir practice and attend a discussion group once a week. It's amazing to be able to have that little bit of time, if I want to go out and have a coffee with a friend I can." **Valerie**

Norman had a recent assessment and the support was changed from his previous replacement care to work for him as well as his wife. "It was the fact that they listened to us as a unit; they tailored the support we get and now this gets us through on a weekly basis." **Norman, Hertfordshire**

# Key Learning and Themes

This work enabled us to listen many people, and some messages were particularly loud and clear and warrant a mention as essential factors contributing towards carers' rights and wellbeing becoming a reality throughout the journey. The reality in these areas is apparently not in line with the aspirations of the Act. And whilst the majority of this guide is focused on presenting what works, we want to ensure that the messages of some of the challenges are taken as priorities to move forward.

## Advocacy

Carers regularly raised /raise the issue that they don't know about their rights and entitlements in law. Many have simply not heard about the Care Act (2014), the Equalities Act (2010), or the Mental Capacity Act (2005). They are not aware that the Care Act gives them an entitlement to independent advocacy if they are having substantial difficulty in taking part in the process and don't have an 'appropriate individual' to support them, during assessment and support planning. Whilst these criteria may not apply to many people in caring roles, it is essential that this support is available for those who need it. For others there is still a need for issues based advocacy to be an option, helping them negotiate the legislative landscape and ensuring their rights are upheld. This gap is often filled currently by advice and guidance organisations. However this project suggested further exploration into advocacy, carers and the Care Act is needed.

## Peer Support

Carers told us time and time again that what they really valued was the opportunity to talk to other carers who were sharing similar experiences to their own. Yet sadly the backdrop of austerity and changes facing the social care sector means that activities which facilitate peer support have seen significant cuts. A focus on individual assessment, eligibility and budgets has diverted attention and money from the interest or topic based group activities which many carers claimed were/are their lifeline. The importance of peer support for the emotional and social wellbeing of carers was central to the numerous stories and accounts we listened to. Carers organisations told us that when there is an activity on offer this is a successful way of drawing carers in. They said it was also helpful to ensure that these were cyclically restarted so that recent carers don't have to try to "break into" existing friendship groups, which can be difficult.

## Personalisation

This project took us full-circle in our question about how personalised support can deliver positive outcomes for carers. As we developed our ideas about the different elements of the 'carers journey' it became clear that some aspects of the journey are better developed than others. Experiences over the past year suggest that there remains a lack of clarity about what personalisation is and what good looks like. Whilst elements of community-based support and access to universal services appear to be implemented, often by local third sector organisations, access to personal budgets and truly person-centred support plans remains minimal. Some people seemed unaware of the flexible and person led nature that these should offer. A greater understanding of self-directed support and the structures which can help make this happen for carers and families needs further development and work.

## For Further Reading...

Carer friendly communities

<https://www.carersuk.org/for-professionals/policy/policy-library/building-carer-friendly-communities-research-report-for-carers-week-2016>

The state of caring 2016

<https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016>

Carers Strategy – link to be released soon

Working with carers in a family centred way

<http://www.skillsforcare.org.uk/Documents/Topics/Supporting-carers/Assessing-carers-needs.pdf>

## Films:

Identifying as a carer

<http://www.carersresource.org/carers-talk-video/>

Reaching carers under the care act

<http://www.carersresource.org/carers-wellbeing-video/>

## Acknowledgements:

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