Assessing carer’s needs

A short guide to taking account of everyone in the family who cares
Introduction

Most of us live in families. These can be in one place or many places, made up of relatives or those that we think of as relatives. Families have changed greatly in the past century, with work, children, relationships and older age now changing how families look and feel.

Most care happens within families. Often, families do everything possible to minimise the need for formal care and support. Often with complex inter-dependencies, they juggle giving the support and care that members might need, using the skills, relationships and trust that has been built up over many years between them. To families, ‘personalised support’ is the norm; they find what works for them.

Carers play a critical role in reducing the need for formal care. They are often the lynchpin between the person being cared for, social care, the GP, and other care workers and professionals. They provide an important network of support from within the family, from friends, neighbours and the local community.

Carers and the wider family should be seen as expert partners and actively involved in shaping how support is delivered when it is needed. This short guide, aimed at those working with carers and families, will help you to take a whole family approach to carers’ assessment and support planning, ensuring families are supported in the best way to care for as long as they wish, or are able, to do so.

“I pop in to see my mother in law on the way home from work. She needs a bit of shopping popping in every now and again, so my niece sees to that whilst she is in town. She loves doing this; she has a learning disability but loves to help people. My wife makes it a bit easier for her by helping her with her banking once a week. We all get by helping out where we can.”

Grateful thanks to David Trumper of Bath and North East Somerset Carers’ Centre for his help with the development of this guide.
It’s not always easy to identify carers, and they often don’t identify themselves.

Meet the Leishmans

Sonya Leishman is 38 and was diagnosed with Multiple Sclerosis at the age of 21. She lives with her partner Michael, and their three children. Michael gave up work to care for Sonya four years ago, and their 14 year old eldest daughter, Jenna, also carries out a large amount of caring. From a very early age she has been helping with personal care tasks such as washing and dressing as well as helping out with her younger siblings. Jenna sees this as just helping out with her mum. Jenna struggles with juggling this with her schoolwork and social life, and has been bullied at school. This all had an impact on her mental health and she started self-harming. Eventually, Jenna felt able to talk to a teacher at school who understood young carers’ issues and put her in touch with her local young carers’ service where she now receives support. She is feeling able to cope much better and is hoping to go on to college when she leaves school.

A carer’s assessment can help to identify who in the family is caring and what support is needed by everyone identified.

Meet Annie and Ian

“You just do it and get on with it and don’t think anything about it.”

Annie, 93, has cared for her son, Ian, who has a learning disability, for over 50 years. Annie still supports and guides Ian throughout daily life, and Ian now does lots to help his mum manage everyday tasks. Both Annie and Ian are supported daily by Ian’s sister, Sandra, who lives nearby.1

Many people don’t recognise that they are a carer, or they think that because others do more, their own role in caring doesn’t really count. As in this example, because there is someone seen as ‘primary carer’, sometimes other carers aren’t identified or supported. Some communities do not recognise the term ‘carer’ which can make identifying carers particularly difficult.
Meet Kevin, Elizabeth, Beth and Kevin’s Dad, Brian

The Kennedy family all live together in a small flat in a large town. Kevin is a carer for his wife, Elizabeth who has severe epilepsy and for his daughter, Beth, aged 8 who is profoundly deaf.

To help with the caring, Kevin’s Dad, Brian, moved in about 18 months ago. In his 60s, Brian has his own health problems, having been diagnosed with bowel cancer, but is able to support around the home and is loved by young Beth, who is also a great help to her Mum.

Between them the Kennedys have developed a routine which means each member of the family is supported. A social family, there are also lots of good neighbours and friends who chip in to support now and then.

By looking beyond the immediate relationship between one carer and one person with care needs, maximising the wider network of support as a resource it is more likely that any support will be successful in enabling the family to stay as independent as possible.

A carer’s assessment which only looks at Kevin’s caring role for Elizabeth will not capture the complexity of the Kennedy family’s situation. Brian and young Beth are a vital part in keeping the Kennedy family going.

Although Beth has her own disability she is a young carer for her mum and her granddad. Neighbours and friends play their part too.

You can help by making sure you are looking out for young carer and making sure every family with a young carer is put in touch with their local young carers service: http://local.direct.gov.uk/ LDGRedirect/index.jsp?LGSL=300&LGIL=6

Images created by www.penmendonca.com
Many carers do not live with the person they care for, often adult children caring for older parents. These carers are often juggling work and other family responsibilities and travelling to visit the person they care for. This can have a significant impact on them financially, at work and in their other relationships.

Caring at a distance

Meet Lydia, caring for her father James

Lydia is in her 40s and works as a care home receptionist. She is caring for her father James who is 70. James lives alone and is having radiotherapy for prostate cancer. Lydia also has a ten year old daughter. James can’t drive and has mobility problems as he has arthritis. Lydia regularly travels over 100 miles round trip to take him to and from his course of radiotherapy which is lasting for three months. They are struggling to afford the cost of petrol, and Lydia is increasingly exhausted and worried about the effect on her daughter as she is away so often. Her employer is supportive but she is becoming worried about having to rearrange her shifts so often.
Existing legislation ensures that carers have the right to an assessment, further strengthened by changes in the law, proposed in the Care Bill. The Care Bill explicitly allows assessments to be combined, this could be the assessment of a person with care needs and a carer, or multiple carers including young carers.

Inevitably, when families care together there is overlap in terms of information and support. Everyone gets irritated by repeating information to a succession of people or the same person for seemingly different purposes. Equally, when support is identified for the person with care needs, it can also meet some of the needs of the carer(s) involved. Enabling the person with care needs to have some respite care is a good example of this for many families; each gets a break from the other. For these reasons, some organisations use ‘joint assessments’, an approach of one assessment for the person with care needs and their carer(s). For some, this will work well. However, there are some cautions with this approach.

Some people welcome being assessed together as they feel this avoids repetition and gives a full picture of their needs. However, there are tasks about which a carer may not feel able to express their own feelings or needs – particularly, for example, if they are finding the caring role difficult or wish to reduce the amount of caring they provide. Also, it may be that the person with care needs and the carer have very different views on what they want from the situation they find themselves in. This is clear when the carer may wish to stop caring. It is unlikely that this need can be fully addressed by a joint assessment.

When there are several carers providing care, several carer’s assessments may need to be undertaken to ensure each carer gets the support they need. Carrying out multiple carers’ assessments may be time consuming but will be worthwhile in terms of understanding the family and so being better able to provide appropriate and meaningful support.

A useful place to start with this process may be to look at the following diagram, based on the Kennedy’s family situation described earlier.

In situations where several members of the family are involved in caring, they may not always agree on the best way to support the cared for and there may be conflict. Everyone must always be offered an individual assessment, and if a combined assessment is undertaken, individuals should be offered the opportunity to talk further on their own if they wish.
Meet the Khan family

Mr and Mrs Khan are aged 78 and 82. Mr Khan has diabetes which has impacted on his physical health and mobility and his eyesight. He also has deteriorating memory. Mrs Khan is struggling to cope with his needs, as she is also beginning to experience worsening health and is increasingly depressed.

They were offered an assessment of their needs, which they both agreed to. However, when carrying out the assessment, the assessor felt Mrs Khan was perhaps agreeing to her husband’s opinions rather than expressing how she felt.

The assessor asked to speak to Mrs Khan separately at a later date and was able to establish that she required extra support than she felt able to state at the combined assessment.

Carers can feel guilty, and may not want to express feelings of frustration, worry or exhaustion. Particularly in a family where many are caring, they may feel that expressing these feelings could have an immediate impact for other carers in the family. Therefore, whether a carer’s assessment is delivered as part of an assessment for the person with care needs, or stand-alone, it is vital that the carer gets a chance to express themselves properly and in confidence.

Whilst it is positive to identify all those involved in caring, this often does not translate into how services are themselves organised. For example identifying an older carer, a carer with a learning disability and a young carer in one family may truly reflect the make-up of the family, but support for each of these people may be located in different services. Often, carers can fail to be recognised because the person that identifies them is from an agency that doesn’t work with particular groups of people and that person then fails to see it as their responsibility to make the links with those who do.

Those with a statutory responsibility for supporting carers need to develop and enforce protocols that allow this to happen; those working with families need to be aware of how to get help from other agencies.

Personal budgets offer the possibility for families to design support that works for them in a way that is not constrained by some of the above factors.

There are points in the “caring journey” when close co-operation and joined up working between various organisations and services are of critical importance to families who care. These may be;

- when caring begins
- when the nature of the caring changes
- when one of the carers becomes ill or less able to assist
- when someone is admitted or discharged from hospital.

At each of these points, it is vital that those supporting the family can work constructively together to support the person with care needs and their carers, regardless of boundaries.

Using personal budgets to support carers – Meet Esther and Kai

Esther cares for her son Kai who is 24 who has multiple disabilities and needs overnight support. He enjoys spending time with his friends and also wants to become more independent. He lived at home until recently, but he wanted to move into his own accommodation.

Esther was worried about this, but worked with the local authority to arrange accommodation in a shared flat with another young man with support needs where care workers can stay overnight. A team of personal assistants share the care for Kai and his flatmate to support them in living independently, paid for through a personal budget, although Esther still regularly spends four or more hours a day caring for Kai and stays overnight when needed. Esther receives support from an independent living scheme to manage the budget as she did not want to take this on herself. Now that the package is in place, Esther feels she has more of a life of her own. She receives a personal budget as a carer for her own needs, which she uses to enable her attend day trips and social events with a group from her church which she feels gives her a break and helps her keep in touch with friends.
Caring within a family; positives and negatives.

Families are complicated and when a member needs care and support, it can put strain on relationships. By the circumstances of a member needing care, families often have little choice but to care, and this can change the whole way that the family ‘works’. Family members will have pre-existing relationships with each other, and any tensions can be highlighted when they have to take on extra responsibilities such as caring. When one member of the family ends up taking on the majority of the caring, perhaps through living closest whilst other carers are caring at a distance, this can also cause tensions and the carer may need support to negotiate with other family members regarding this. Conversely, sharing care can bring family members together. It is important to be aware of both of these possibilities as you work to support the carers within it.

To support whole families in caring we need to

- Recognise that caring is complex and often involves more than just one carer, and there is no ‘typical’ caring situations.
- Find solutions involving the whole family and wider informal network of support.
- Identify hidden carers, especially young carers.
- Build support which empowers carers and their families and is sustainable.

The challenges

Working with carers in a family centred way has some challenges. Here are some, with some possible solutions;

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<tr>
<th>Challenge</th>
<th>Possible solution</th>
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<tr>
<td>Many carers do not think of themselves as a carer, they see caring as just doing what anyone would do in their situation. This may be particularly true if they are not obviously the main carer. Services for carers tend to reinforce this by referring to primary and secondary carers. This approach fails to recognise the subtlety and complexity of each situation.</td>
<td>Describe what a carer does, instead of using the word carer. This may help people see that they are caring. Listen in a non-judgmental way to how the whole family is managing, identifying and acknowledging strengths and skills of the family and each individual. Build solutions with the family that build on these skills and strengths.</td>
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<td>Some communities do not recognise the term ‘carer’. In some communities and cultures, caring in not recognised and can be seen as part of a child’s, spouse or relative’s duties towards the person with care needs.</td>
<td>Again, describe what a carer does, instead of using the word carer. Listen and gain an understanding of how caring is seen within the culture of the family.</td>
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<td>Not all carers will ask for or accept support from their family or friends with their caring role, for a wide variety of reasons.</td>
<td>Make best use of personal budgets to allow carers and families to design solutions that work for them. Don’t make the assessment a once off offer; saying “no” to help now, doesn’t mean that a carer will always refuse support.</td>
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Ensuring carers assessments recognise and support the whole family

- Recognise that every caring situation is unique and often complex and there may be a number of people caring and being cared for.
- Take time to understand the caring role being played by everyone in the family; even if they are not a relative.
- Think about young carers and ensure they get the support they need.
- Remember that people with care needs themselves may also be carers in their own right.
- Remember that not everyone recognises the term ‘carer’. Try asking who helps looking after the person.

- Support the whole family to identify solutions which will meet their needs rather than imposing pre-determined ideas.
- Enable the whole family to support each other as much as possible and stay independent, but consider the impact this has on each member.
- Give real options to assess separately or together. If combining assessments, make sure the carer is able to express their view.
- Refer to local carers’ services such as carers centres.
We hope that this short guide has helped you consider a whole family approach in your work with carers.

For more information on working with carers, please see www.skillsforcare.org.uk/carers and www.carers.org