

PART 6: Guidance for people supporting carers with learning disabilities to use this pack

This section is for you if you are a worker, advocate, friend or family member supporting someone to use this pack. The pack has been designed as a resource you can work through to help a person with learning disabilities think about if they are a carer, what they are doing and if there is any support they'd find helpful. This section gives you more information about carers with learning disabilities and using the pack.

People with learning disabilities can be carers too

The number of people with learning disabilities who are becoming carers is growing. People may be caring for elderly parents, husbands, wives, partners, friends or housemates. Like other carers, many people with learning disabilities are happy to care for others and proud of what they are doing as it seems a natural role to take on. However, again like other carers, this does not mean that they do not need some help in the role and that they have been supported to make decisions about the type and amount of caring they are doing.

Some of the key issues for people with learning disabilities who are carers include:

- Generally not being recognised for their role as carers
- Not always being offered many choices about continuing to care or the way that other support is being provided
- Fear from both the person with learning disabilities and the person they care for of being judged and separated if others discover the extent of the care being provided
- Lack of information that is accessible and easy to understand about peoples rights as a carer, support that might be available and the different health conditions that the person they care for may be suffering with
- Lack of practical support with some tasks that might make a big difference, such as with shopping, changing light bulbs, getting to appointments, getting the right benefits, planning and cooking meals
- Feeling very isolated and having reduced opportunities for friendship and breaks.

All of the points above are issues that all carers often struggle with anyway. However, the struggle is even more difficult if a carer has a learning disability.

The difference between 'helping out' and 'caring'

Many people with learning disabilities do a lot to help out at home or with family and friends. However there is a distinction between 'helping out' and 'caring'.

Most people are encouraged to do as much for themselves as possible and we all do things to help with the running of our homes, friends and families. However, when a person becomes a carer, it is likely that the person they care for would not be able to manage to live or cope as independently in the community without their support. Sometimes the support given is clear to see, such as preparing meals, pushing a wheelchair or helping a person with their personal care. At other times caring can be less obvious but no less essential, such as providing emotional support, companionship, making sure someone is safe in their own home and taking their medication.

Sometimes what starts as 'helping out' evolves into caring. It's important to be aware of this and to watch for signs that a situation is changing. For example:

A woman with learning disabilities was known to be living at home with her elderly mum and they were considered a great team – both seen regularly together shopping at the local centre and having a great laugh together. One Monday, a key worker at the daughter's day service noticed that she had brought in sandwiches made with mouldy bread. When she asked about it, the daughter became very distressed and said her mum wouldn't listen to her when she said the bread was mouldy and that she didn't understand why her mum had kept asking her the same questions all the time. The key worker contacted social services and helped the daughter explain what was happening at home in more detail. She was clear that she didn't want to be split up from mum but she did want help to understand what was going on and with practical support at home. A social worker for mum and a separate one for daughter then worked together to put in more support at home for things like cleaning, shopping and taking mum out whilst the daughter was at her day service. The situation was monitored very closely and eventually the daughter became unable to carry on caring at home and helped to choose somewhere for her mum to live that was nearby so she could visit a few times a week.

Making the most of this pack

There is a lot of information in this pack but it has been divided into different parts to try to make it less daunting to people with learning disabilities. Whilst it is not essential to go through every section with them in detail, the information is there if a person wants it and it should help them work out if he or she is a carer and the sort of help they might need. **It is important that you try to read through the pack before using it with a person so you are familiar with what's in it and can pick out the right sections that might help a person with any questions or concerns they might have about being a carer.**

If you aim to complete the form with a person to find out how much care they are providing and what support they need, then try to plan to do it in a place the person feels comfortable and relaxed and able to talk openly.

Although the person being cared for does not have to know what is happening, it may be appropriate to help them understand the importance of looking at the person with learning disabilities' needs as a carer and the process involved. This may need to be handled very sensitively as some people will be worried that they may be separated or forced into making decisions they are not happy with. **It should be stressed that the overall purpose of the process is to provide the help and support needed to both the person being cared for and the carer to enable them to stay as independent as possible for as long as possible.** It is not unusual for there to be *mutual caring* happening, particularly in older families, where both the person with learning disabilities and the older person are looking after each other. In these situations it may be important that both people are encouraged to have both a carers' assessment and an assessment of their individual needs also.

If you are not sure if the person with learning disabilities is a carer then you should start with Part 1 of this pack: '*Am I a carer?*' The three questions posed in the first box may help them understand that they are a carer, that the pack is for them and that completing the form together should be useful.

10 Main Steps for using this pack:

1. Familiarise yourself with the information in the pack. You may need to find out from a social worker whether there are already systems or forms used to support people with learning disabilities who are carers specifically. E.g. Shropshire has a Carers Assessment form specifically designed for carers with learning disabilities
2. Talk to the person with learning disabilities, and where appropriate, the person they are caring for about the pack. Discuss any concerns they may have about the process and any possible repercussions.
3. Check if the person wants anyone else to be with them – like a family member, key worker or advocate
4. Make sure you go through the pack somewhere they feel safe and can talk openly
5. Plan enough time or meetings to go through this information and complete the form without it feeling rushed
6. Go through the 3 key questions in part 1 with the person you are supporting to check if they are a carer
7. Talk with the person and use the pack to answer any questions they may have and to explain the purpose of completing the form together
8. Complete the form. Remember, the first part is to help a person understand their own needs, the second part is about the help they provide as a carer and the third part is about help they need. It is very easy to fall into the trap of thinking about the person's needs as someone with learning disabilities all the time rather than thinking of their needs as a carer
9. Make sure you fill in the Carer's Plan at the end of the form. Help the person think about what needs to happen now and what might need to happen in the future. There will probably be a range of outcomes, from practical support to emotional support from someone remembering to ask if they are ok and how things are at home to pick up on whether their needs are changing
10. Make sure the form is used and followed up on regularly. If you cannot put the actions into place yourself, make sure a copy of the form is passed on to someone who can help, such as a social worker or key worker.