

Moving On

a carers guide to the emotions and the process when the learning disabled person you care for moves to their own home



LEARNING DISABILITY CARERS VOICE

Quote from a carer

'All things, good and bad, come to an end. Even the most perfect set up in the family home will eventually come to an end. Without planning for this, the risk of sudden, massive, and rapid change is possible at a time when there could be grieving and great emotional turmoil. Not the best time to weigh up life changing decisions. Other family members will not be immune from this turmoil and will not be in a position to make good decisions for all.'

'Like making a will, laying the foundations of how your child will live when you can no longer care is in itself a part of the caring process. It is best done with a calm background, while you still have all your powers and energy.'

1) Why is it an issue ?

- Most carers struggle to make the first move, because facing the future and accepting that you are preparing for a time when you are not there, or can no longer do it, is a really difficult thing to do. Sometimes the barrier to getting started is a very simple one – we don't know where to start...and through this leaflet we aim to help in that.
- Although most of us concentrate all the time on what the person we care for CAN do, thinking about the future and about them managing without our help can cause us to become afraid about whether they really could manage.
- On the other hand, helping the person you care for to move on is very much safer whilst you as a carer are still there, still have energy, and can rescue the situation if things don't work out.
- Some of us hope or assume that our other children may take on our caring role. Be very careful about doing this. They may be willing to support their brother/sister, but offering full-time support may be the last thing on their list, and could cause resentment if it is forced upon them.
- Many of us struggle to envisage somebody else looking after the person we care for as well as we do...and of course they won't – but in some ways they may do it better.
- Even if it all goes completely according to plan, be prepared for the fact that it will be an emotional time both for you and for the person you care for, and that both your confidence and theirs about what you are doing will fluctuate from day to day.

2) Range of options available

- The Local Authority has already produced a guide to the main options – called ‘A Home of my own ‘ This is available both in written form and online at <http://www.kirklees.gov.uk/community/ld/index.asp> Also, have a look at Connect to Support – a website where providers of care advertise what they have to offer. Web address www.connecttosupport.org/kirklees
- It is always worth seeking out other carers who have been through the process. Their solution may be different to yours, but they will have learnt a lot on the way. Carers Count might be a useful source of contacts for this.
- Look at what the peers of the person you care for are doing, and try to visit some of that provision. List the strengths and weaknesses of each as you see them, because this helps to narrow down what you are after.
- Consider joining with other carers to establish the sort of place you want if you cannot find anything satisfactory. Direct payments can provide a means of financing it once an organisation gets it set up.



3) How do you get started, and what does the process involve?

- As soon as you begin to be clear that a move might suit the person you care for – even if it a few years away – register that with the social work team. They try to stay up to date with the future need for accommodation, and it can take up to five years for the Local Authority to get the funding, the site etc for a new provision.
- The fact that you have registered that interest does not mean that you are under pressure from that day onwards. The timing of the move must depend on when it is right for those directly concerned.
- When you are at the point where you as the carer(s) and the person you care for are in agreement that the time is right, you need to start the process by contacting the social work team. Be aware that the process can be very lengthy, and you may need an emergency plan in place in the meantime.
- If you are aiming for something that already exists, the first thing to do is to ask for an assessment of needs for the person you care for from the social work team. This will consider their needs after they have moved on, not what you already have in place.
- As with all assessments, be aware of how significantly it will affect the package of support that is offered. The Local Authority only has to make provision for the most essential needs – which may be less than what you would like to see.
- Our previous booklet ‘Getting the best from the assessment process – a carers guide’ will provide you with guidance about how to handle the process.
- As part of the process, the assessor will want to carry out a mental capacity test, to check the extent to which the person you care for

understands the decision they are making, and is happy with what is going on. The assumption is that they have this capacity, and even if they don't this does not stop a move on. It just means that people who know them have to get together to make what is called a 'best interests decision' – which confirms that they all agree that the way forward is for the person to move on.

- Throughout the process, things should move at a pace that suits the person you care for, and gives them the time that they need to feel confident about what they are doing. Many will need a lot of time to check and re-check the plan, and to talk about anything they don't fully understand yet.
- At some stage in all of this, it will be worth checking that they are getting all the benefits that they are entitled to. The social worker will be able to arrange for this. Depending on the nature of the accommodation they want to move to, they may well need to claim Housing Benefit.

4) *What happens when something becomes available ?*

- The final decision about what is going to be right for the person you care for rests with them, in collaboration with you if they want help to decide. It is vital that you try to disregard your own fears, and concentrate on supporting them to make the right decision.
- Perfect solutions are rare, and in reality there will always be trade-offs and compromises...but stay as close to the ideal as you can.
- Given the importance of the decision, it must not be rushed, and there must be plenty of opportunities to find out about every aspect of the place they might be moving to. Be honest, not polite. Do not feel embarrassed about asking whatever you need answers to, and visit as many times as

you need to.

- If there are things that are troubling you try to work out why you feel as you do.
- If you cannot find solutions to your concerns, then say no. It takes courage to do that, and there is always a fear that it might be a while before another offer comes along... but finding that courage will be far better than spending time trying to rescue a situation that simply isn't working.

5) *Fears and fantasies*

All carers who begin down this track will have their own fears and fantasies about it. Some of those we have come across most often are

- How do the finances work
- Will the mix of people work
- Will others take advantage of them
- Will they like and be liked by the other people there



- Who will fight their corner when I am no longer around
- Will the care be good enough
- Will they be under pressure to move on, rather than being able to see it as a home for life
- What will happen if their health or mental capacity deteriorates
- Will they be safe
- Will medical conditions get the attention they need
- Will they be happy
- Will they feel we have pushed them away

We haven't got smart answers to all of these but can reassure you that most, if not all, sort themselves out. This is another reason to support the move whilst you are still around to seek solutions.



6) *Preparing for the move*

- Consider a 'trial run' in the form of tea-time visits or a respite stay, both to build up the individual's confidence and self-esteem and to assess the likely success of a more permanent move.
- Involve other family members in the the decision-making if they want to take part.
- Be honest about what it will involve, but encourage the person you care for to want to move
- Reassure them that they will still be part of the family, and still have regular contact.
- Be involved from day one with choosing room furnishings and all the other practical things that begin to make it all real and build up a feeling of ownership. Doing it in small steps makes it less scary.
- Be positive – even if you don't always feel it.

7) *What is your role after the move?*

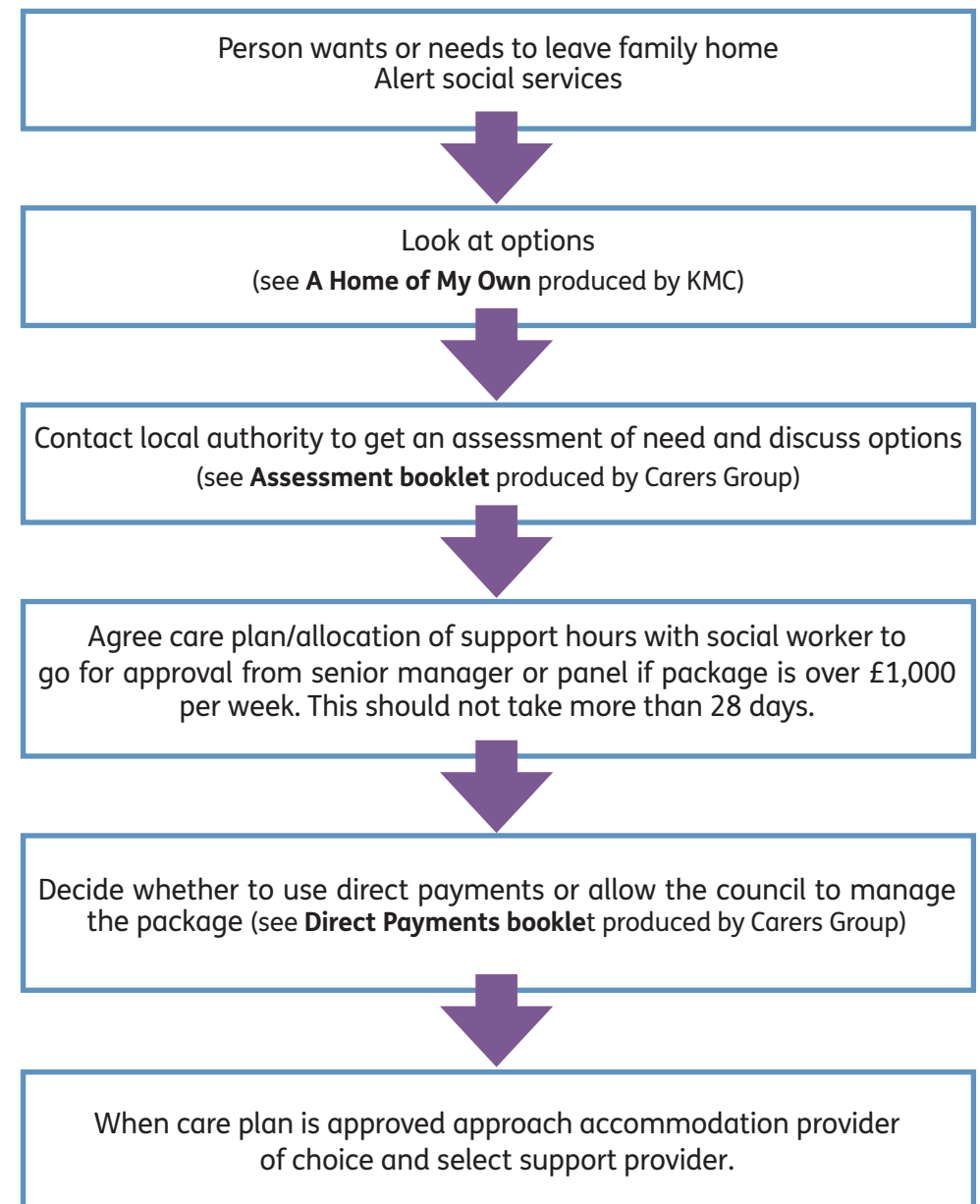
- Be in touch regularly. You know the person you have cared for, and will recognise what they are feeling sooner than others. All forms of contact will give reassurance, and help to build their confidence in their new home.
- Be prepared for the fact that they may be delighted with their new life, and wouldn't consider returning to live with you.
- Make sure that there are regular reviews of the situation. These are important when things are going well, as well as when they are not.
- As time goes on, there will be changes of staff, changes in the other residents, and in lots of different aspects of their lives. You will be an important point of continuity.

- Your emotions will probably be all over the place. Feeling empty. Feeling redundant. Feeling proud / scared / anxious.
- During the long settling-in period, it is vital not to keep pulling them back home for your needs. They need time to build up an investment in their new setting, and it may be better to spend time with them there rather than inviting them back home. Involvement with practical tasks like buying clothes or going with them to medical appointments can be an easy way to stay in touch without disrupting. Walk around the neighbourhood with them. Eat at local pubs. Visit local shops. All of this emphasises that this is now their base.
- Once they have settled in, overnight stays will be fine – but be aware of how easily the balance can tip, and overnight stays can become unsettling.
- Over time, it will be important to arrange transfers to a local doctor, dentist etc

8) What about support afterwards ?

- Put effort into keeping a good rapport with the staff team, because they will be the first line of support now.
- If there is a need for somebody to be a safety net, then another family member may be best..or an advocate from an agency like Cloverleaf.
- Don't be afraid to accept that their departure allows you to have a new life, too, and there is nothing to feel guilty about if you start to enjoy it !

LEAVING HOME FLOW CHART



This document has been prepared and published by a group of family carers who care for adults with a learning disability, and who are working to build up a network of family carers which is independent of the Council. Please consider joining the network.

Details of this and other information is on our website

www.ldcarersvoice.co.uk

It is one of our aims as a carers network to 'support carers to become as well-informed and powerful as the organisations they have to deal with.' The production of this booklet is another contribution to achieving this aim.

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