

# Supporting Older Families to Prepare for the Future

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## Supporting older families to prepare for the future - first steps

This factsheet is based on an article written by Dalia Magrill (Sharing Caring Project, Sheffield Mencap and Gateway) for DSA's Journal (Autumn/Winter 2015)

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Most families worry about what will happen to their relative when they are no longer able to care or be involved. These worries can build up and become overwhelming as people grow older. No one knows what the future holds, but there are lots of practical steps that families can take to start to prepare for the future – you're probably already doing some of them without realising.

The aim of this factsheet is to share practical tips and ideas of things your family can be doing to prepare for the future of the person you support. As every person and situation is different, it is not possible to provide a definitive list of things that you must do. What is right for one person will definitely not suit someone else and what happens in one area may be different the next county over. Some of the ideas may strike a chord with you, others you may adapt to suit your situation or simply dismiss as not relevant to you. What's most important is that even if you feel now is not the right time for you to make plans, you do understand the process, who might be able to help and how, for when you do feel ready.

It is important to note that some areas may be more proactive than others about forward planning with families whilst others have no clear process.

## **When's the right time to start planning for the future?**

There is no 'right time' to start planning for the future as it is different for each family and dependent on the different future options being considered. For example, if you and the person you care for decide the plan for the future is for them to move elsewhere, but in the local area so you can be close by, then the only way to be sure of the best choice and match with others (if relevant) is to start making your wishes known early so that any opportunity is not missed out on.

For many, peace of mind is being able to see a relative move, become well settled and know they are happy before any crises occur and whilst you are able to help smooth the transition process. If your family are considering other options, such as your relative staying on in your home in the future, then again there are steps you can start taking now such as beginning a conversation with the local authority in order to put a plan together.

There are two key things that you can do before making plans for the long-term future:

### **Get the right support in place now**

It is very difficult for people to be able to focus on where and how a person may live in the future if they are not being supported to have a good life now and you are all not getting the help that may be vital to preventing crises.

Families need to be able to trust that services will get things right in the future and that means that services need to start building strong relationships with you now. The right support now may include your relative enjoying activities which gives you a break too and which help them reach their goals e.g the right equipment in place to help you all, some help in the home to help out with practical tasks and/or someone coming to support your relative to go out and about and give you a break at the same time.

### **Put your 'emergency cushions' in place**

Preparing for emergencies and thinking through 'what if' scenarios is a key step in getting ready for the future; it hopefully brings a level of reassurance to all as well as providing key information for long term plans. If you think of 'emergency cushions' as the different things you can do to try to minimise the impact of any unexpected situation, the more cushions you put in place, the more protected your family will be in a crisis.

Emergency cushions can include:

- Having a key safe and identified key holder
- Carrying a carer's emergency card
- Having a care alarm fitted with a red button or pendant for use in an emergency and where possible, teaching your relative how and when to use it
- Mobile phones and home phones with pre-programmed emergency contacts in
- Making sure your emergency contacts know who to contact in different scenarios
- Making an emergency plan – which includes how long your relative can be on their own safely, what daily tasks they will need help with, how they communicate and other issues.
- Register the emergency plan with various key people e.g. social worker, GP, emergency contacts
- Keeping important information together e.g hospital passports, copies of recent assessments, person-centred plans etc
- Ensuring your emergency contacts know where to find the important information

Setting up the cushions will help all of you to start thinking about what may or may not be viable options for the future e.g. whether your relative may be someone who prefers to be with other people rather than being able to spend periods of time on their own.

## Preparing for the Future

Once you have the right support in place to continue to cope now and feel more confident around what will happen in an emergency or crisis, the following tips will help you to plan and prepare for the longer-term future.

### Start talking (and listening)

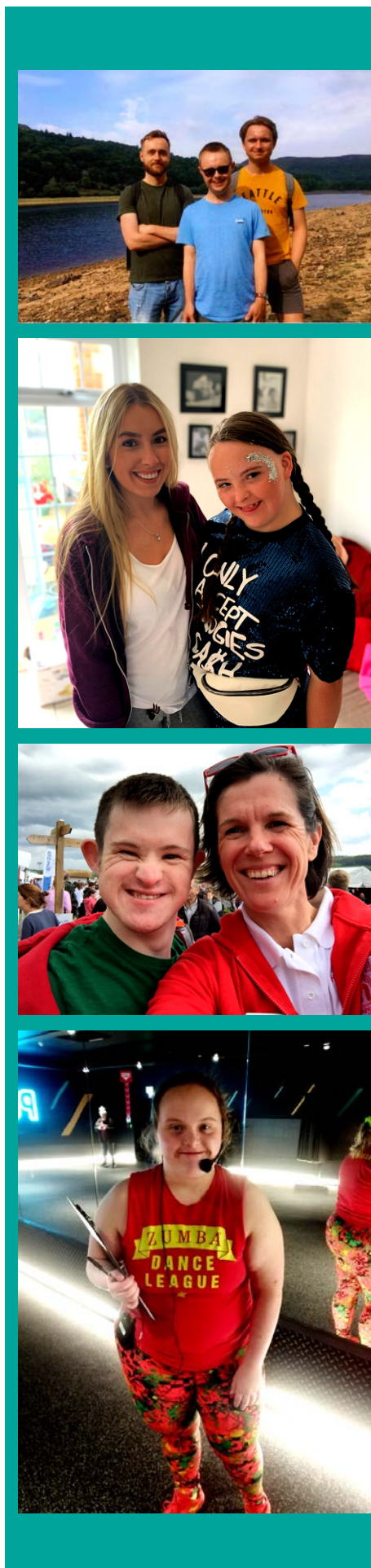
Many families have worried about what will happen in the future for decades, but never spoken out loud about it much because it is so hard to face. Sometimes even between parents, one person has different ideas to the other. It is really important to start discussing the future and having the difficult conversations with each other, wider family members and the person you support, so that people are clear on what is and isn't expected of them and what they feel willing and able to do in future. It is often the case that once you start talking out loud you can easily find common ground for moving plans forward. If it is hard to be the person who raises the topic, how about asking someone neutral to help, such as an advocacy worker or carer support worker?

### Find out what's available and the planning process where you live

It is really important for you to find out what options are available and what happens with future planning where you live as every area works differently and have their own procedures. There are many creative options for people to get the housing and support they need, but this needs to be balanced with what support they are assessed as eligible for by the local authority. For example, if the preferred option is for your relative to stay in their own home with support throughout the day and night, that may be more than the local authority is willing and able to fund dependent on their needs assessment. For many people with very high support needs, this may be a more feasible option than for people who appear more able. Other options include people having their own tenancies with support available at key times, but staff on site all the time; sharing a tenancy with others; shared ownership schemes or even living with other families. Remember that 'independent' or 'supported' living does not mean that people will be on their own – they will have the right level of support that they need (this can include 24 hour support if appropriate).

It is really important to explore what options are available in your area. If there appears to be nothing suitable and you find other families who share your hopes, it is always worth approaching your local authority to see if they may be interested in developing something new. The earlier you start, the more options and choices available, but remember to keep your information up to date as things can change.

You will find further information about housing at DSA's website (see link at the end of this factsheet).



## **Keep the person you care for at the centre of everything**

It's important to ensure that the person you care for is involved in planning for the future where possible. It can be really difficult to discuss with them, particularly if there are no timescales for a change or you are worried that they will become distressed at the thought of changes. The reality is that many people are often more aware than we realise, particularly if they watch soaps or know people from their services who have faced crisis or moved suddenly.

Workers who know them well may be able to raise issues you struggle with and it may be worth talking to them (or advocates) to work out a way of sensitively finding out their views. If people are not able to verbally communicate, it is still important to think through what they would like and again it could be useful to enlist others who know them well, such as respite and day services staff. Build a picture of what would and wouldn't suit them e.g. a person with very complex needs liking to be with lots of other people so that there is always someone to watch and lots going on.

## **Get up to date assessments – for you and the person you care for**

The person you care for may be eligible for support from the local authority and is entitled to get their needs assessed to determine this. If their needs are eligible and they receive a service then this needs to be reviewed regularly. The assessment and reviews should cover all aspects of their life. You are also entitled to a carers assessment if you provide, or intend to provide, regular care and support. This includes if you are supporting someone to live away from home or intend to.

The assessment process (see link to Care Act guidance about assessments at the end of this resource) is crucial to planning ahead as it gives all of you and the local authority the opportunity to discuss what may or may not be feasible to fund in the future. What a local authority is very unlikely to do is commit to saying what they definitely will/won't do in the future because unless a change is actually being planned now they just can't say; there are too many factors that are unknown and it would be wrong to give false hope. The best they are able to do is give you an indication of what they might do if needs don't change.

## **Start practising for the future**

If the plan for the person you care for is to live more independently then it is never too early to start building up their skills and confidence. This can include starting to let them spend some time on their own and even building up to evenings and then nights and weekends on their own, maybe with support coming in from an agency or worker they are used to. In many ways this is the only way for people to get a real idea of what they might want for the future and how it might be. It also gives you peace of mind and confidence, knowing how well they can manage. Similarly, start supporting people to learn to use the kitchen more or help with shopping and money.

You may want to discuss how best to do this with an occupational therapist or build it in to an individual budget, so that people can get used to support from others, especially because people will often do more for other people than they will for their families!

## **Put your financial affairs in order**

It's important to put your financial affairs in order and to check that you have taken appropriate steps (including looking into Discretionary Trusts if you are thinking of leaving any money or property to the person you care for). Similarly, it is worth looking at appointee services and starting to get advice about who is available to support your relative to look after their finances in the future.

## Make sure everyone knows the plan

It's important that you make sure that people who need to know about plans for the future are clear about what is wanted and why. If there are specific options that are ruled out for various reasons, be clear about why that is. Too much information gets lost at times. Many families write down information for people for the future and put together photo books and details of all the small things they do that make a difference to people's lives – the kind of detail that isn't captured in an assessment, but makes a big difference to the day to day for the person.

### Get connected

It is important to think about whether there are people who can look out for your relative in the future and support them to speak up if they are not happy or to notice and speak up if something is wrong.

Many siblings, other family members and friends take on this role, but there are also voluntary organisations and advocacy services who can help or provide support. Make sure you link up to these networks and start talking with other families who are in similar positions to you – it really can help.

We appreciate there's lots of information in this factsheet and you may be feeling a bit overwhelmed at this point. So where to start? Find someone you trust to talk out loud to and begin to have the difficult conversations. Perhaps you could show them this factsheet and it might be a way of starting the conversation.



## DSA Support

If you have any questions about the issues here, you can call the Helpline 0333 1212 300 and speak to one of DSA's information officers or email using [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

You can also contact the following DSA specialist advisers using the details above:

- **Chris Watson (social care and housing)**
- **Helen Wild (benefits and finances)**

In addition, we can put non-urgent medical questions to our medical advisers on your behalf. If you require this service, please speak to one of the information officers.





## DSA Resources

### Housing and Social Care

[Housing & Support For Adults - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

### Benefits, Finances and Banking

[Benefits & Finance - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

[Bank-Account-Managing-Money.pdf \(downs-syndrome.org.uk\)](#)

### Wills and Trusts

[12-wills-and-trusts-2022.pdf \(downs-syndrome.org.uk\)](#)

### Making Decisions

[Making-Decisions-post16.pdf \(downs-syndrome.org.uk\)](#)

[LPA-Factsheet\\_.pdf \(downs-syndrome.org.uk\)](#)

### Getting Older

[Ageing-Final-Format-5th-April-DSMIG.pdf \(downs-syndrome.org.uk\)](#)

### Dementia

[2018.09.Alzheimers-Disease\\_DSMIG.pdf \(downs-syndrome.org.uk\)](#)

## Other Resources

### Care Act Guidance

[Care and support statutory guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

### Thinking Ahead: A planning guide for families

[Thinking Ahead Planning Guide.pdf | Together Matters](#)

