

# Planning for the long term

## Introduction

**As people with an autism spectrum disorder (ASD) age, so too do their parents, and often this means support responsibilities are passed on to siblings and other family members.**

Whilst the effects of ageing on people with an ASD are still not fully understood, there are some practical measures families can think about in advance, and steps they can take to make things easier.

If you have a family member with an ASD you may well have considered who will take over responsibility and support for them once their parents are no longer able to. This is a relevant concern whether the family member is living in a residential home with 24-hour care, or still in the family home being supported by parents. The needs of adults with an ASD vary considerably and so, therefore, will the planning. Any future plan will be unique to your family member's situation and needs. The points discussed here might help you to formulate a plan.

## When to plan

For some families there may not be time to plan for a change in circumstances. A sudden illness or bereavement may force you all into a situation whereby you have to make quick, and possibly well-meaning but ill-informed decisions. It is preferable, if possible, to make plans well in advance, when things are settled and you can consider your options carefully.

Some siblings of people with an ASD report that their parents can be reluctant to talk about the future. It can be an uncomfortable topic to discuss for many people, but, even if parents don't seem to wish to discuss future plans for a family member with an ASD, they are likely to be worried about them. Many parents of older people with ASD have refused outside support in the past; however, if they can be encouraged to accept some support now, however small, it may encourage and reassure them to seek more in the future.

There are numerous reasons to encourage parents to be involved in future plan decisions, and some of these are outlined below.

- Parents are the 'experts' when it comes to their children. They know them better than anyone else, and therefore are amongst the best placed people to decide on appropriate plans for the future.
- By planning now, parents will have greater involvement, and their wishes will be taken into full consideration.

- It is easier to start to make changes now, than for someone to have to cope with bereavement and perhaps a change in accommodation for example at the same time.
- Planning means that changes can be made gradually, reducing anxiety for all as much as possible.

## **How to plan**

Your family member with an ASD and everybody involved in supporting them should be involved in creating a plan for the future. People may have differing ideas which will need to be considered carefully, and an external facilitator can be helpful, for example a social worker or family friend.

It is helpful if the plan is written down, made available to all those involved in supporting your family member, and reviewed on a regular basis - for example once every two years unless a significant change happens in the interim.

## **What to plan**

A good starting point is to establish a shared view of the future. In particular consideration should be paid to the following.

- Where will your family member live in the future? Will they be able to continue to live where they are currently? If not, what are the other available options?
- Who will provide care if required? If it is family members, is this a suitable long-term option?
- Who will advocate on your family member's behalf, if required?
- A financial plan, which includes benefits, earnings, any money that may be bequeathed and so on. It is advisable to seek independent financial advice. A person with an ASD may be missing out on entitlements, as may their carers. Does the person need help to manage their finances? Who will provide this?
- A health plan. Ensure you have all health contacts. Consider family health in general and any conditions that run in the family: is the person with an ASD at increased risk of cancer, heart disease, etc? What things should people look out for? This information should be passed on to future carers.
- A social plan to ensure the person is not isolated. Who visits them - family members or other people, too? Would a befriender be beneficial? Could they join a club, evening class or social group?
- Who will you, as a carer, need support and advice from?
- Are you aware of your family member's rights and entitlements, and your own as a carer?

- Are you fully aware of how much support your family member currently requires and receives? It may be that their parents are providing far more support than anyone realises. Consider asking parents to keep a diary for a month of all the support they offer to get a clearer picture.

### **Other preparations**

Make sure you have a list of useful contacts for your family member. Here are some you may need.

- Health – GP/MD, consultants, psychologist, psychiatrist, community psychiatric nurse (CPN), learning disability nurse, optician, counsellor, dentist, out-of-hours emergency numbers.
- Social care – social worker, care manager, etc. Out-of-hours emergency numbers.
- Residential service - manager and key worker contacts.
- Care agency staff.
- Housing contacts – landlord, agency contacts, etc.
- Day centre contact details.
- Banking details and contacts.
- Benefits details and contacts.
- Employer's details and contacts.
- Local neighbours; anyone who has a key to their home.
- Befriender's and advocate's details.

Likewise, check that all the people who need them have your details and those of other family members, should they need to contact you in an emergency.

One idea is to create a 'This is my life' or 'All about me' book for your family member. The book acts as a useful resource for family members in an emergency, or when the time comes for them to take over responsibility for their brother, sister or family member. Such a book might contain information on the following.

- Dates for appointments: hospital, optician, dietician, dentist, counsellor, community psychiatric nurse, psychologist, psychiatrist, etc.
- Details of all medications currently taken and any allergies; who is reviewing, prescribing or monitoring these? Who is making sure they are administered correctly?
- Details of any health needs. For example, does your family member suffer with depression? Are they prone to chest infections? Are they on any special diet? How do they exercise?

- Daily life schedule – morning and bedtime routines, usual meal times, weekly schedule of day centre visits, work, volunteering and so on. Who are the contacts for these activities?
- Things your family member can do for themselves - for example getting dressed, paying bills, personal care.
- Things they require support with, for example shopping, cooking.
- Likes and dislikes – people, food, drinks, places, clothes, etc.
- Triggers that may affect mood and anxiety levels, including any sensory issues.
- Anxiety indicators – how do you know when he or she is becoming anxious?
- Strategies that are used to manage behaviour and reduce anxiety. What has been tried? What works?
- Communication – does anything aid communication? What forms of communication are used, eg PECS, Makaton, visual supports?
- Hobbies and social activities. Does your family member have any special interests that are very important to them?
- Friends and other people who are important. For example befrienders, advocates, etc.
- Transport – how does he or she get to work or their day centre? Who is the contact?
- Dates for future care review meetings.

As part of this process it is useful to find out where important correspondence is kept, or consider starting your own file.

## **Getting support**

### **Carers emergency scheme**

Some local authorities run carers emergency schemes. These offer slightly different things in different areas, but some include workers who can help you to draw up an emergency plan, which is then held by the scheme. Carers carry a card with a unique number and the scheme's telephone number, which can be called in an emergency.

### **Support from social services**

If social services are not currently aware of your family member, now would be a good time to ask them to do a community care assessment, to find out what support they are entitled to. They should also carry out a carer's assessment for you. If your family member already has a social worker it is important to keep them informed of any changes that occur.

## **Checking benefit entitlements**

You should make sure that your family member, and those caring for them, are receiving their full benefits entitlements. You also need to be aware how these entitlements could change if living and care arrangements alter in the future.

## **Getting involved**

Many siblings report being 'sheltered' from the pressures of caring, whereas others have been heavily involved from an early stage.

You may now feel that you would like to be more involved. Below are some ways you might do this.

- Attend review and planning meetings.
- Visit your family member's home or day centre. Many residential homes have an 'open house' policy, and families can visit whenever they wish. Attend any social events they hold.
- Attend any available training opportunities.
- Ask for help. If you are worried about your family member's behaviour or anxiety for example, seek advice from professionals and other people who know your family member well.
- Make sure you are clear about the support your family member is currently receiving and how this is funded. Ask for a copy of their care plan if they have one. Find out what other options may be available.

## **Thinking of yourself**

You may have many other responsibilities in your life, and already be juggling work and caring for your own children. Below are a couple of things to consider should you take on a caring or more responsible role for your family member with an ASD.

- Be as informed as you can be about your rights as a carer.
- Tell your GP/MD that you are a carer, so that they can help you to look after your own health. As a carer you may be entitled to the flu jab.
- Tell your employer (where applicable) that you are a carer. You may be entitled to flexible working arrangements.
- Request a carer's assessment from social services. You may be able to access respite through this.
- Ask for support from other family members or friends.
- Make time for yourself.

- Be realistic about what you can do and seek support where necessary.

Feedback from a sibling survey found that some family members, such as young nieces and nephews, do not understand their uncle or auntie with an ASD, and may in fact feel frightened of them, or resent the time they take up. It is important to involve all the family, and reassure and listen to youngest family members. You may need to encourage children to talk about their anxieties or the mixed feelings that they may have.

## **Other things to consider**

### **Bereavement**

The likelihood of a bereavement increases for everyone with age. You may find it useful to find out about bereavement and ASD in advance.

### **Sharing experiences**

You may find it useful to share experiences with others in a similar situation to yourself.

### **Making decisions**

Your family member may not be able to make some, or all, decisions independently. It is important that they are supported fully, and their wishes considered in any decision-making process. Siblings may have to establish their legal status in relation to dealing with their brother's or sister's affairs in a way that parents do not. A Lasting Power of Attorney may be necessary.

## **Summary: planning for adult siblings**

- Plan in advance if possible.
- Make sure a community care assessment has taken place, and social services are kept informed if any support needs or circumstances change.
- Make sure that you, if you are a carer, and your sibling are receiving your full benefit entitlements.
- Keep a list of all useful contacts.
- Make your contact details available to anyone involved in your sibling's life who may require them.
- Find out if your local authority runs an emergency carers card scheme.
- Prepare a 'This is my life' or 'All about me' book.
- Start thinking about changes you can make gradually now, to reduce the number of changes which may be needed in future, and avoid too much change having to take place at any one time.
- Be as involved as you can now – and be realistic about the effects of this commitment on your own life.

- Be as informed as you can.
  - Think about how your family member would cope with a bereavement in the future, and ways to prepare and support them for this possibility.
  - Think about planning for a time when you might be unable to continue providing support.
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I freely admit this is 'nicked' from the National Autism Society's website and can be found at:  
<http://www.autism.org.uk/living-with-autism/parents-relatives-and-carers/siblings/planning-for-the-long-term.aspx>

So all credit goes to them for this useful article!