

## Planning Ahead: Things to Consider

As much as it can be hard to think about the future, it is important to do so as it is much better for family carers who know their relative so well to be involved in any decision making, rather than leave it to those who do not have the same knowledge and understanding.

Planning ahead can feel overwhelming and is not always easy or straightforward. It can also be very emotional. We recommend involving as many people as possible who know your relative well so that you feel supported along the way. We would also suggest breaking down the planning and not try to do everything at once. Prioritise those practical things that take time to put in place, such as financial planning and developing a crisis care plan. Then work on the other areas which give a more detailed insight into who your relative is and how they like to be supported when you have the time and feel ready to tackle it.

What follows is an overview of all the areas we feel will help you start to develop a better picture of your relative, what support they may need as well as both yours and their hopes and dreams for the future.

### Involve other people!

Include siblings, extended family, and friends as they bring other perspectives and ideas. Local parent support networks, social services, other people in your relative's life who knows them well. Siblings can be left to sort out without knowing anything about their relative's needs.

### Decision making and planning for the future

Key decisions will need to be made around:

- Where they will live
- How their finances will be managed
- How they will be supported
- Who will be responsible for keeping an eye on things?

Understanding the ability of your relative to **make decisions**.

- Mental Capacity Act
- Best interest decisions
- Challenging decisions
- Involving other people in decision making
- Other people who have authority to make decision (Power of Attorney, Court of Protection, Deputyship)
- Advance decisions to refuse treatment (living will or advance directive) specifying what medical treatment they would not want to receive at some time in the future.

### Person Centred planning and making plans

- Involves gathering information about your relative and using the information to solve problems and create more opportunities.
- It starts with the person rather than the services that are available.
- Helps think about what would work well for your relative in the future.

## Building friendship and support networks

- It is important to have a network of people involved in our lives not just parents.
- Can be there to support your relative when the parents are no longer around.
- How can they be supported to continue this network of friends/support network?
- The more people around them, the safer they are likely to be.
- Especially important for those who find it hard to communicate to have people speak up for them.
- Use a **circle of support** to help build networks. Think about how to keep it going. This is especially important when your relative moves out of the family home and when you are no longer able to be as involved. Arranging for your other relatives and friends to have regular contact helps give the message to the support provider that as a family you are still committed to your relative having a good life.

## Talking about difficult subjects

This can be hard and uncomfortable to do as parents often feel protective and find it hard to know how and when to broach sensitive or complex subjects. However, open conversations may help with anxiety and in the long term help them to talk to the right people and keep safe.

- Puberty
- Relationships
- Sexuality
- Dependency
- Getting older
- Ill health and ageing in loved ones.
- Bereavement
- End of life planning

## Gathering memories and life stories

This can help people with learning disabilities to develop and affirm their sense of identity. This is particularly important when someone moves away from the family into their own home. Creating a photo album (folder) or a memory box is an effective way of helping your relative remember their life story.

## Financial Planning

Leaving something for your relative with a learning disability could provide them with additional choices and enable them to spend money on things as their needs change. However, leaving money must be done in a way that will enable your relative to continue to get support from adult social care and means tested benefits but is also recognised by the law. Things to be considered include.

- Making a Will
- Discretionary or disabled person's trust
- Leaving your property in a will
- Appointeeship and suitable persons
- Trustees
- Letter of wishes

## Housing and Support

Finding the right supported accommodation to enable your relative to leave home is challenging and emotional as you need to make a proper choice about what will work best. No one size fits all. It can also take a long time to plan and if/when your relative does move away from the family home it does not mean that you will not be involved in their life.

- Think about what would work best for your relative, not what 'spaces' are available with the local authority.
- Talk to other families and find out about their experience and any recommendations or tips they may have.
- Do you know of other families in a similar situation who you can work together with?
- If your relative will need funding for support, talk to the local authority about your plans to ensure that adequate funding will be available.
- Make sure your relative's name is on the housing register so the local authority knows about their potential housing need.

### Funding responsibility of a local authority

If your relative requires funding from the local authority for their housing and support needs, they will need to have a [care act needs assessment](#). They will also need to meet the [Fair Access to Care Services \(FACS\)](#) criteria to check that they are eligible for funding.

### Housing Options

There are a range of different supported living options available. Take your time to research the different options so you and your relative can decide which might suit them best.

- Shared House
- Shared Lives
- Residential Care
- Extra care Housing
- Intentional Community
- Core and Cluster
- Network (Key ring – national organisation)
- Renting a flat/house on own
- Shared or outright ownership
- Family investment
- New build – housing association or private money
- Specialist buy to let
- Private sector leasing

**Rented Housing:** Can the tenancy pass to their relative (succession)? This is not always straightforward so you will need to check with the landlord.

Can succeed to the tenancy in Local Authority Housing if there has not already been a succession. Check if can do a joint tenancy.

No right to succession with a registered social landlord.

**Tenancy Agreements:** May have to apply to the Court of Protection for deputyship for the tenancy agreement to be signed if your relative does not have capacity.

**Assured Tenancy:** Offered by registered providers such as housing associations, specialist not for profit providers and properties previously managed by local authorities.

**Assured short hold tenancy:** Mainly offered by private landlords.

**Rent:** Housing benefit is determined by the type of landlord. If your relative rents privately, you are restricted to a locally determined capped figure set by the local district council known as Local Housing Allowance (LHA).

If they rent from a registered housing provider (HA) or not for profit landlords, they may be able to have more or all their rental costs met, even if higher than a LHA.

### Choosing a support provider

If your relative is offered a place in a house by the local authority, it may already have a support provider in place so you may not be able to choose who provides the support provision for your relative. There are things you can do and ask however when viewing a home that will help you make an informed choice.

See the **Check List: Questions to ask Support Provider for things to look for** in the Supported Living Section

## Keeping an eye on things after a move

**“You are not handing over your relative, you are just stepping aside”.**

It may take a while for your relative to settle into their new home and it will be a time of worry for you as you watch other people take on the support but also pleasure as you see them start to settle into their new situation.

Your relationship may gradually change as you step back from the caring role, but you should be able to stay as involved as your relative would like and hopefully you will see them become more confident in their new home.

A good support provider will welcome family involvement. Communicate with them regularly let them know how and how much you want to be involved. Discuss any concerns at an early stage as this makes them easier to resolve.

Make sure your relative is involved in any decisions – ask the support provider how they are involving them. Family members should always be involved in the process of assessing whether your relative has the capacity to make a specific decision and in making best interest decisions.

If you do have concerns, you can ask for an independent advocate to be involved to ensure your relatives wishes are properly understood or, alternatively you can follow the complaints procedure.

If you have concerns

- Raise them straight away however small.
- Listen to any concerns your relative may have – watch for changes in their behaviour.
- Talk to the house manager first, then the area manager if you feel your concerns are not being addressed.
- If you think your relative is at risk of harm, you can follow the Safeguarding of Adults procedure.
- Otherwise follow the organisation's complaints procedure.

## Health

It is a well-known fact that people with a learning disability have worse physical and mental health than people without a learning disability. It is important that when planning ahead for your relative, you work closely with the support provider who will be supporting your family member to ensure they understand any health issues they have and that they carry out all regular health checks.

A number of barriers stop people with a learning disability from getting good quality healthcare. These include:

- A lack of accessible transport
- Patients not being identified as having a learning disability
- Staff having little understanding about learning disability
- Failure to recognise that a person with a learning disability is unwell
- failure to make a correct diagnosis
- Anxiety or a lack of confidence for people with a learning disability
- Lack of joint working from different care providers
- Not enough involvement allowed from carers
- Inadequate aftercare or follow up care

Other things to monitor are:

- Annual health checks
- Flu immunisations
- Cancer screenings
- Menopause

Common associated health conditions for people with a learning disability include:

- Mental health problems. A learning disability is often confused with mental health problems.
- Epilepsy
- Being underweight or overweight
- Dementia (particularly high in people with Down Syndrome)

### **Reasonable adjustments**

A lack of reasonable adjustments can be a barrier to accessing health care settings and to equal healthcare. Health care professionals have a legal duty to provide reasonable adjustments for disabled people which can include easy read information, avoiding medical jargon or longer appointment times.

Oxford Health have a learning disability liaison team including an epilepsy specialist nurse based at the JR who will support people with a learning disability when attending appointments in hospital.

### **Resources**

[Thinking Ahead: a planning guide for families](#)

[The Challenging Behaviour Foundation](#)

[Planning Ahead Cards for people with learning disabilities](#) (You Tube)

[Planning Ahead Cards \(Templates\)](#)

<https://www.macintyrecharity.org/our-approach/death-and-dying/>McIntyre: Dying to talk Project