



sense

connecting sight, sound and life

Decisions to make, steps to take

A guide to planning long-term
care and support for disabled adults
and their families.



Contents

Decisions to make

- 4** Where will my loved one live?
- 6** Who will pay for care and support?
- 9** How can I make sure my loved one is financially secure?
- 9** Welfare benefits
- 11** Who will support my loved one to make choices?
- 13** Longer term advocacy support
- 15** What support is available for family carers?
- 16** What are the legal rights for my loved one?

Steps to take

- 19** Decision-making checklist
- 20** How can I support my loved one to make choices for themselves?

**To find out more about Sense's
When I'm Gone campaign go to
www.sense.org.uk/helpfamiliesplan**

Introduction

We have created this toolkit to give you the information you need to start making plans for the future

At Sense, we know that many family carers of disabled adults with complex needs have worries about what will happen when they are no longer able to provide support. Despite this, few feel able to put plans in place for the long-term future.

For some of you, it just doesn't bear thinking about – for others, confusion about how the system works and what support may be available can be a significant barrier. You may also lack the confidence that local services will be able to meet your loved ones' needs.

We know that planning for the future can be a challenging thing to do; it takes time, and the systems involved can be complicated and difficult to navigate.

Considering plans for the future can also be emotive and difficult to think about. But having a timely plan in place is vital to ensure your loved can achieve their aspirations and hopes for the future.

That is why we have created this toolkit; to give you the information you need to start making plans for the future. It is intended to be a simple guide to the main options available, your legal rights and the key decisions you will need to make.

It is never too soon to plan for the future; plans can be updated and changed as many time as they need to be. The important thing is to begin the process and take steps towards securing peace of mind for the future.



1

Decisions to make

Where will my loved one live?

There are many different types of social care and support available for your loved one

Understanding the main types of housing available will help you to start thinking about what would be the most appropriate form of support for your loved one, and to narrow down the options. If you are clear about the types of choices ahead, you can also plan to best way to involve your loved one in the decision-making process.

Social care is support for people to remain healthy, happy and independent in their own communities. The majority of social care services will be arranged via your local authority. Your local authority will assess needs and identify which types of support are most suitable.

The main types of social care to consider are:

- **Residential care:** This is long-term care provided within a residential care home. Some care homes provide nursing care and many have specialist expertise in supporting certain disabilities or conditions. Most provide 24 hour-a-day support.
- **Supported living:** This is an arrangement where an adult has their own tenancy within specialist or adapted accommodation, and receives help from a care and support provider to live independently.



Individuals in supported living arrangements can live by themselves, or with other people who have similar support needs, who they will share living costs with. They can choose where they want to live, who they want to live with, how they want to be supported, and what happens in their home.



Your loved one may be able to access community-based services to meet their health, social and wellbeing needs

- **Homecare:** Homecare is where a person lives in their own home (rented or owned by the individual or their carer), and receives practical and personal care support from health and or social care services. Homecare is sometimes referred to as domiciliary care or care at home.
- **Shared Lives:** Shared Lives is a model of care where your loved one is matched with an approved shared lives carer. Some disabled adults move in with a shared lives carer full time, and others have regular visits arranged to their home to support them to remain as independent as they would like to.

- **Family and friends:** You may have family and friends who would be willing to provide a home for your loved one. Siblings are sometimes willing to take on this responsibility, although for many families this will not be appropriate.
- **Day services/community-based services:** Regardless of the type of accommodation you choose, your loved one may also be able to access community-based services to meet their health, social and wellbeing needs. The types of services available will depend on where you live, but could include day centres and local social groups. This may be provided by your local authority or by charities that are based locally.



Who will pay for care and support?

There are several different ways that care and support can be funded.

Funding from social services

You may be able to get funding from your local authority social services department. This is usually called social care funding.

Under the Care Act 2014, every local authority must undertake an assessment for any adult who may have care or support needs. The assessment will look at what a person's needs are, and what support would need to be put in place to meet those needs.

You should contact your local council to ask for a social care needs assessment. To find your local council go to: www.gov.uk/find-local-council

Once your local authority has completed their assessment they will draw up a

Care and Support Plan to set out what your loved ones' needs are and the cost of providing for them. You should be provided with a 'personal budget' which is the amount of money that has been allocated to delivering the support described in the plan.

Each disabled person will have a financial assessment to see if they need to pay anything towards the cost of support. Social services may pay for the whole cost of someone's support if they have low income and savings. The threshold is currently £23,000.¹

Direct payments

Individuals or their family carers can take on the responsibility for spending their personal budget that has been allocated by social services. They can do this by requesting a direct payment. This is where the local authority gives a personal budget directly to the individual. It is paid into

Every local authority must undertake an assessment for any adult who may have care or support needs





an individual's bank account, though some authorities use 'top-up cards'. The individual or their family will then spend the money to meet their social care needs by purchasing services and employing staff.

Direct payments will not be appropriate in all cases, but should be considered for individuals who are able to take on the responsibility. Taking on a direct payment is entirely optional – your council cannot make you take a direct payment, and you can opt instead for an Individual Service Fund (ISF) - where your council gives the personal budget to a care provider, who uses the money to plan and deliver an individual's care and support on their behalf.

Alternatively you can request a council managed personal budget – where the council holds the personal budget, and commissions services on behalf of the individual directly.

Funding from the NHS

If your loved one has 'substantial and ongoing' care needs due to a complex medical condition or disability, you may be able to secure funding from the NHS. People with a primary healthcare need can receive funding towards the cost of care outside of hospital – for example, in a residential setting that provides specialist nursing care, or at home. This type of funding is known as NHS Continuing Healthcare.

NHS Continuing Healthcare is available for up to 100 per cent of your loved one's care. The level of funding allocated will depend on the results of an assessment carried out by a team of healthcare professionals (referred to as a multidisciplinary team). In some cases, following the assessment, social services and the NHS may agree to share the cost of care between them.

ⁱ As of January 2018

People with a primary healthcare need can receive funding towards the cost of care outside of hospital

If you think your loved one might be eligible, you should request an assessment from their doctor or social worker.

Individuals who are receiving funding from the NHS through Continuing Healthcare also have the right to have a Personal Health Budget (PHB).

A PHB is an amount of money that is made available for an individual to spend on their healthcare and wellbeing needs. This could enable you to choose which services you would like to use and who you would like to provide it.

The amount is agreed and provided by Clinical Commissioning Groups (CCG) – groups of GPs who commission NHS services in your local area.

A PHB is not extra money, but is a different way of spending money that would already have been spent on providing care to the individual. PHBs are optional and support can be administered directly from the NHS.

If you would like to apply for a PHB, or need more information, talk to the local NHS team which provides most of your loved one's care.



How can I make sure my loved one is financially secure?

Wills

By leaving a will you can set out your wishes for your estate (your money and any property you own) after you have died. Your nominated Executors will have a duty to ensure that your wishes are followed in terms of who benefits from your estate but not how this is taken forwards. It is possible to include a letter of wishes in your will, in which you can indicate how you would like any money left in your will to be spent or request some specific expenditure, but this isn't legally binding.

Trusts

A trust is a way of looking after property and money for disabled people who are not able to manage assets for themselves. A trust is an effective way to safeguard benefits and entitlements for your loved one. A solicitor can help you to setup a trust and advise on what should be included in it. If arranged correctly, having a trust will not impact on means tested benefits or eligibility for funding from a local authority.

If you have left financial assets to your loved one in the form of a trust, the management of the trust, including how the money is spent, will be carried out by trustees. You can appoint trustees yourself when you set it up and you can set out the terms of how you would like the trust to be managed on behalf of your loved one.

For more information on Wills and Trusts and how to set one up, visit www.mencap.org.uk/wills-and-trusts.

Welfare benefits

There are a number of welfare benefits that your loved one could be eligible to receive:

- **Personal Independence Payment (PIP)**: is a benefit designed to meet the extra costs of having long-term ill-health or a disability. It is available to disabled adults aged between 16 and 64 who need help with their daily living and mobility. PIP replaced the Disability Living Allowance (DLA) in England and Wales in 2013.
- **Employment and Support Allowance (ESA)** is a benefit for people of working age between 16 to 64, who are unable to work due to illness or disability. People who receive ESA will be placed in one of two groups – the work-related activity group, where they will be expected to seek employment, and the support group, where there is no such requirement. ESA replaced Incapacity Benefit (IB), Income Support (claimed because of a disability) and Severe Disability Allowance. If your loved one still receives these benefits they will be assessed for ESA.
- **Attendance Allowance** is a tax free, non-means tested benefit for disabled people aged over 65 years old. The allowance is designed to meet the everyday cost of living with a disability. Attendance Allowance is paid at two different rates with the amount allocated depending on the level of support needed.

A trust is a way of looking after property and money for disabled people who are not able to manage assets for themselves

If your loved one is in receipt of welfare benefits, these can be managed by someone other than the person who receives them

- **Housing Benefit** can help individuals, including disabled people, to meet the costs of rent if they are on a low income. This can also help meet the cost of rents and service charges for people in supported living settings. Housing Benefit will soon become payable as part of Universal Credit (see below).
- **Disabled Facilities Grants** are provided by local councils. The grants help towards the cost of essential adaptations, to enable disabled people to continue to living at home.
- **Universal Credit** is a single monthly payment for people in or out of work and under State Pension Age. Universal Credit will eventually replace a range of other benefits including Housing Benefit, Working Tax Credit, income-related Employment and Support Allowance and Income Support.

You can find out more by visiting www.gov.uk/browse/benefits

If your loved one is in receipt of welfare benefits, these can be managed by someone other than the person who receives them, if appropriate. A family member or a friend can act as an 'appointee'. An appointee is a person who has been chosen by the Department of Work and Pensions (DWP) or local authority to receive welfare benefits on behalf of someone else.

Families should make a written request to the DWP to become an appointee. The DWP will interview you and provide a list of responsibilities.

You can find out more at www.gov.uk/become-appointee-for-someone-claiming-benefits

If your loved one has the mental capacity to manage their own welfare benefits, but would like someone else to do it on their behalf, they can authorise this themselves by granting a Power of Attorney for property and financial affairs to somebody they trust. They can also separately grant Power of Attorney for decisions related to their health and welfare (see page 14).

Appointing a deputy

If your loved one does not have the mental capacity to make decisions about their property and financial affairs, it is possible to apply to the Court of Protection on their behalf to appoint a deputy.

Appointing a deputy is a legal arrangement and will mean that the deputy can support your loved one to make a decision or, where appropriate, make a decision on their behalf about property or financial affairs. Two or more deputies can be appointed to support an individual. You can also apply separately to the Court of Protection to appoint a deputy to make decisions about your loved ones personal welfare (see page 14).

More information on the roles and responsibilities of a deputy and how to appoint them is available at <https://www.gov.uk/become-deputy>



Who will support my loved one to make choices?

An advocate can help someone express their needs and wishes, and weigh up and take decisions about the options available to them

As well as financial considerations, it is important to consider if your loved one will need support to make decisions and to secure the support they need.

Professional support is available to fulfil this role and is usually referred to as 'advocacy.' Thinking about who will provide advocacy is especially important if your loved one is likely to struggle to make decisions for themselves.

Advocacy support under the Care Act

Advocacy is help to enable a person to get and plan the care and support they need, and it should be independent of your local council. An advocate can help someone express their needs and wishes, and weigh up and take decisions about the options available to them. They can help the person find services, make sure correct procedures are followed and challenge decisions made by councils or other organisations.



Every person receiving care and support is entitled to have an independent advocate

Under the Care Act 2014, every person receiving care and support is entitled to have an independent advocate, if they will have 'substantial difficulty' in making decisions for themselves. Your local authority will fund advocacy services in your area, and will be able to advise you about how to access this support. You are also entitled to an advocate if you are a carer and need support.

The advocacy that is provided under the Care Act tends to be arranged to help someone make a decision that will affect their lives in the short term. However, people with more complex needs will need ongoing advocacy support. This allows them to develop a good relationship and understanding with their advocate.

Independent Mental Capacity Advocate (IMCA)

Under the Mental Capacity Act 2005 local authorities and the NHS have a legal duty to provide an Independent Mental Capacity Advocate (IMCA) when making a care decision where the person doesn't have the capacity to make decisions about their care due to an impairment, injury or disability.

The role of the IMCA is to establish what the individual feels about the care decision being proposed and what their wishes are. They must give the person information about the options and present their conclusion to the decision makers. The IMCA also has to ensure that all legal duties are being followed by the decision makers and can challenge decisions made if they feel they don't meet the best interests of the individual.

For more information on the role of IMCAs, visit www.voiceability.org.

Longer term advocacy support

There are several types of advocacy services available for people who need support over a longer period of time:

- **Professional Advocacy:** This means appointing a professionally trained advocate to support your loved one for the long-term. Professional advocates support individuals to make decisions and make recommendations about their ongoing health and care.
- **Citizen Advocacy:** Citizen advocates are volunteers from the local community, who provide support to an individual over a long term period. The volunteer would be supported by a professional advocate.
- **Peer Advocacy:** This is where one-to-one support is provided by advocates with a similar disability or experience to your loved one. Trained and supported volunteers often provide peer advocacy as part of a coordinated project.
- **Circles of Support:** This is where a group of people provide support and advocacy to an individual over the long term, rather than one person providing support. The person with care and support needs is at the centre of the circle; they can choose who is in the group and how they want them to support them to make decisions. Membership of the circle can vary over time and a good circle will include people with a range of knowledge and expertise who can be called on at different times. More information on Circles of Support and how to set one up can be found at www.circlesnetwork.org.uk.

For more information please see: SCIE, Care Act, Types of Advocacy: <https://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/inclusion-empowerment-human-rights/types.asp>



Most advocacy tends to be made available through local charitable organisations



It is important to note that longer term advocacy support is not generally provided by local authorities, and most tends to be made available through local charitable organisations. This means that the type of advocacy support available in your area will depend on where you live.

You can find out more about what is available in your local area on the Opaal website <http://opaal.org.uk/locations/> and by contacting Voiceability: <https://www.voiceability.org/>

Power of Attorney

If your loved one has mental capacity to manage make decisions for themselves, but would like to delegate this to someone they trust, they can grant a Power of Attorney. This would enable them to grant permission to somebody they trust to make decisions about their health and welfare. They can also separately grant Power of Attorney for decisions related to their property and financial affairs.

To find out more visit
www.gov.uk/power-of-attorney

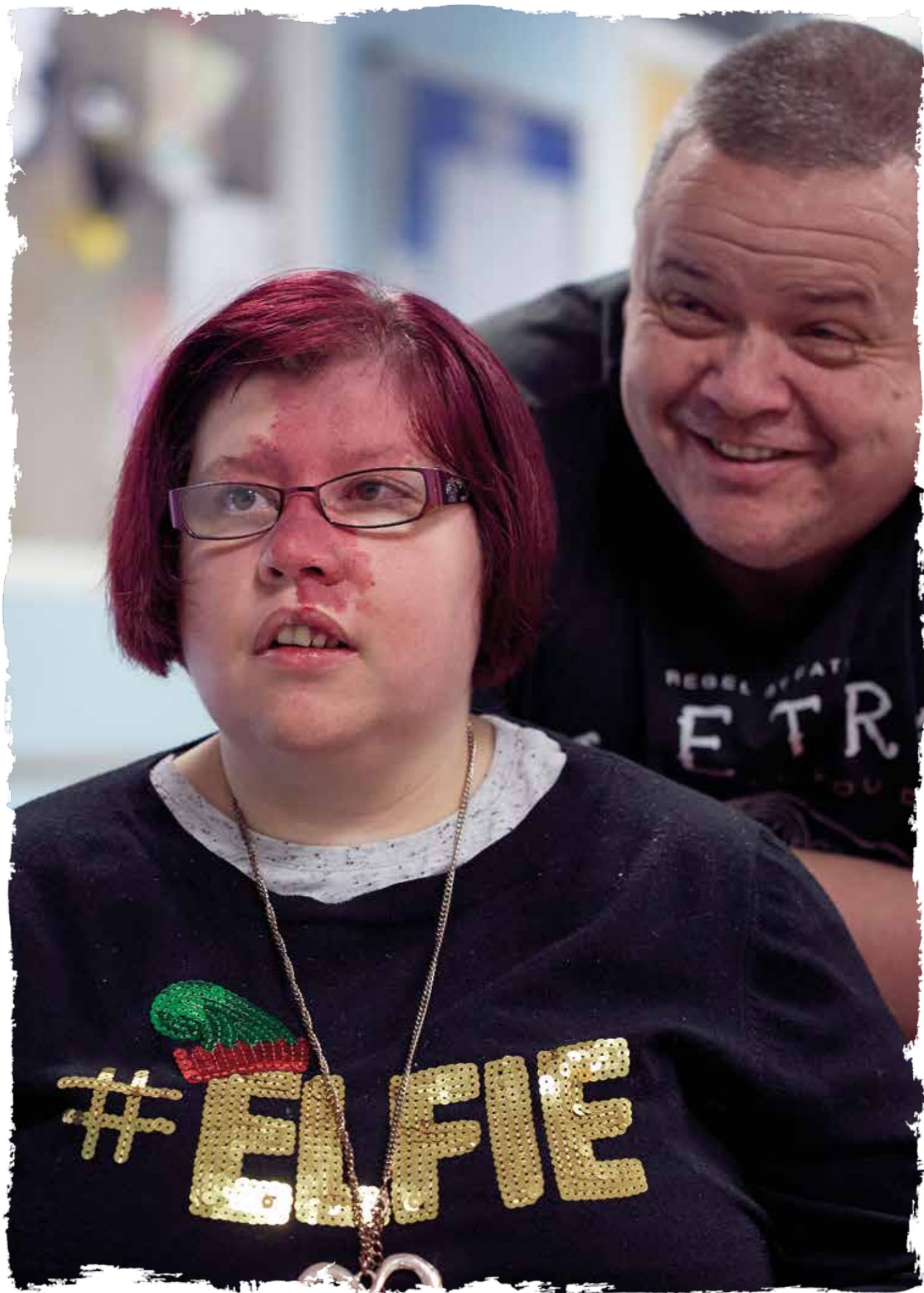


Appointing a deputy through the Court of Protection

If your loved one does not have the mental capacity to make decisions about their personal welfare, it is possible to apply to the Court of Protection on their behalf to appoint a deputy.

Appointing a deputy is a legal arrangement and will mean that the deputy can support your loved one to make a decision or, where appropriate, make a decision on their behalf. Two or more deputies can be appointed to support an individual. Families can also apply separately to appoint a deputy to make decisions about their loved ones' property and financial affairs.

For more information visit:
<https://www.gov.uk/become-deputy>



What rights does your loved one have?

The Care Act 2014 sets out the legal framework for what people with care and support needs should expect from social care.

Local councils have a responsibility to provide the following, and people approaching them to ask for help with care and support should expect these responsibilities to be met:

The individual must be involved in a meaningful way throughout the planning process

- The Care Act has an overarching 'wellbeing principle' which councils must adhere to when delivering and planning care and support at all times. A core part of this principle is that people with care and support needs have a right to live independently and have control over their day-to-day life.
- Councils also have a duty to provide preventative services, this is a vital part of the Care Act which says that care should not simply be a reaction to a crisis, but rather that councils and care providers should work proactively to promote wellbeing and independence.
- All councils in England have a duty to provide an information and advice service – including a signposting service which supports people with care and support needs and their carers to plan for their future care needs.
- For people who would have a 'substantial difficulty' in being involved in the care planning process, councils must provide an independent advocate to support that person and ensure they can make the best decisions about their care and support.
- Care planning must be done in a person-centred way, this means that the individual must be involved in a meaningful way throughout the planning process and services must be developed according to these principles.

What rights do carers have?

As a carer, you are entitled to support. If a friend or family member takes on caring responsibilities for your loved one in the future they will also be entitled to this support.

Carer's assessments

As an unpaid carer, they will have a right to request a Carer's Assessment under the Care Act 2014.

A Carer's Assessment determines the needs of carers and examines the impact that their caring responsibilities are having on them. The assessment also establishes whether they are willing and/or able to continue caring. Following the assessment, the local authority can make resources available to provide respite or practical support to carers.

Carers can request an assessment of their own needs by contacting their local adult social services team. Support is available irrespective of their financial status, the additional support the person they care for receives or the level of need for support.

Information on Carer's Assessments, what they entail and the support that is available at <https://www.carersuk.org/help-and-advice/get-resources/looking-after-someone>

Carer's Allowance

Carer's Allowance is a benefit for people who care for somebody with a disability for at least 35 hours a week. In order to qualify for Carer's Allowance, the person who is being cared for must be receiving a disability related benefit (Disability Living Allowance middle or higher rate care component, Personal Independence Payment daily living component at either rate, Attendance Allowance, Constant Attendance Allowance or Armed Forces Independence Payment).



Claimants must be aged 16 years or over, must not be in full-time education and cannot be earning more than £110 a week after deductions such as tax and national insurance.

More information on Carer's Allowance is available at www.gov.uk/carers-allowance.

There are several sources of support available for friends or family members

2

Steps to take

Now you have a good understanding of the options available for your loved one, the next step is to start making decisions and begin to pull together a plan.

Decision-making checklist

> **1.** Take the time to read through the information in this guide so you understand what the main options are for future housing and support.

> **2.** Use the person-centred planning tools on page 22 to work out what is important to and for your loved one, and involve them in the decision-making process.

> **3.** Based on your expert knowledge as a carer, and your loved ones' wishes for the future, think about the following questions:

- **In their own home with homecare support**

- Will their home be rented or owned?
- Will they live in the home of a friend or family member?

- **In a shared lives placement**

- **With friends or family members**

- Are prospective family carers aware of their rights to claim Carer's Allowance and to ask for their own needs to be addressed through a carer's assessment?

Where does your loved one want to live?

- **In a residential care home**

- Do they need nursing care within the care home?
- Does the home need to provide any specialist to meet needs?

- **In a supported housing development**

- Do they want to live alone?
- Do they want to live with other people?

How does your loved one want to live?

- What are their important routines and activities?
- How will they be involved with families, friends and communities?
- What are their aspirations about education and employment?
- Will they require access to a community or day service?

Who will pay for care and lifestyle in the future?


- Would social care funding be available?
- Would NHS Continuing Healthcare funding be available?
- Would social care and the NHS jointly fund?
- Is your loved one entitled to welfare benefits?
- Could they use their own income/savings or family money?
 - Do you need to write a will?
 - Would a Trust arrangement be appropriate?


Who should help to manage our loved ones finances?

- Would a direct payment or Personal Health budget be appropriate?
- Do you want to set up a Trust managed by trustees?
- Do you need to appoint an appointee to manage welfare benefits payments through the DWP?
- Does your loved one want to grant a Power of Attorney for decisions about property and financial affairs?
- Do you want to appoint a deputy through the Court of Protection for decisions about property and financial affairs?

Who will support your loved one to make decisions?

- Do you want to put long term professional, citizen or peer advocacy in place?
- Would a circle of support be a good model to put in place?
- Does your loved one want to grant a Power of Attorney for decisions about health and welfare?
- Do you want to appoint a deputy through the Court of Protection for decisions about personal welfare?

 **4.** Find out what housing and support services are available in your local area by entering your postcode on the NHS Choices website. The website has a list of home care, shared lives, care homes and supported living providers. It shows the current availability and has link to the most recent inspection reports from the Care Quality Commission (CQC). www.nhs.uk/service-search

 **5.** Contact the adult social services of your local council to find out the options available to you and your family, and to ask for help with planning your care. You can find your local council at www.gov.uk/find-local-council



Concerned you are not getting support?

If you are not feeling properly supported to make choices about the future, you can make a complaint to your council via their official complaints procedure. You can find information about how to do this on your local council's website.

If you are unhappy with the care and support your loved one is currently receiving, and you haven't been able to resolve this informally with the service provider, you should complain to your council. All local authorities must have a formal complaints procedure which will be accessible online. In your complaint you should include what your concerns are and what you would like the council to do in response. You should include any evidence you have to support what you are saying.

If you are unhappy with the response from your local authority, or if they do not respond in a reasonable time, you can complain to the Local Government and Social Care Ombudsman: Find out how at: <http://www.lgo.org.uk/make-a-complaint>

You can also raise your concerns with your elected representatives – your local councillor or MP. You can find their details by entering your postcode at <http://www.writetothem.com> As a last resort you may be able to take legal action against the local authority or organisation providing care. To do this you will need to get expert legal advice.

How can I support my loved one to make choices for themselves?

Use these tools to ensure you have a clear understanding of your loved ones' aspirations for the future

The most important person to involve in the planning process is the person with complex communication needs; where possible they should lead this process themselves.

Other people you may wish to include are close friends and family members, including siblings. You might also want

to seek the advice of health, social care and education professionals who already support you and your family.

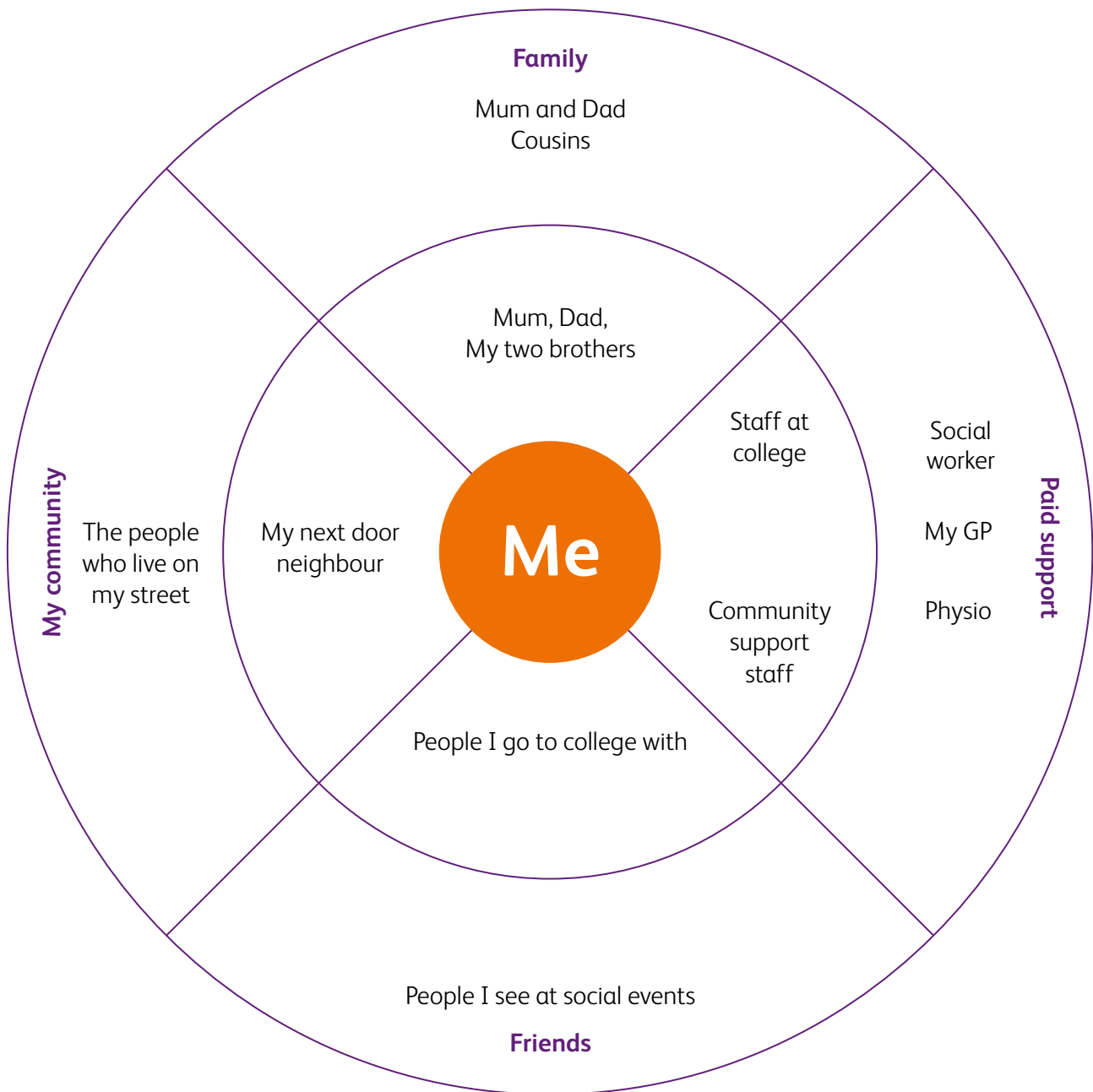
Use the following tools to help guide your conversations, and ensure you have a clear understanding of your loved ones' aspirations for the future.

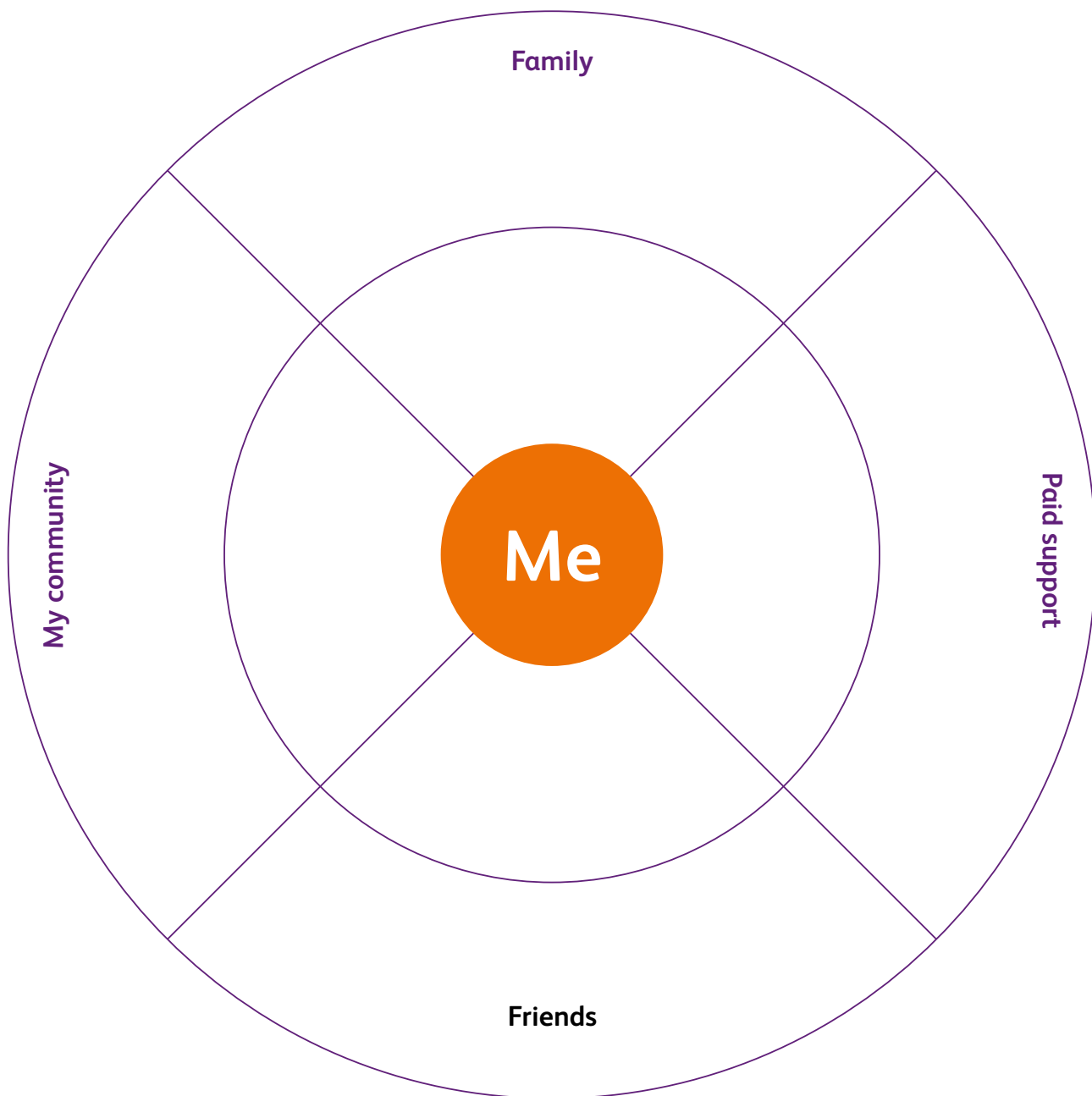


Relationship circle

This tool can be used to identify the people who are most important to your loved one. This could be important when making decisions about who to appoint as Trustees or who else to involve in the long-term planning process. It can also help to identify any gaps or highlight opportunities for increasing number or depth of relationships.

Example












Important to and for me

This tool helps disabled people and their families to think about what is important to and for them. It can help identify likes, dislikes and priorities for the future.

There are two different versions that can be used to help you think about these things. Pick the one which best meets your needs.

Example 1

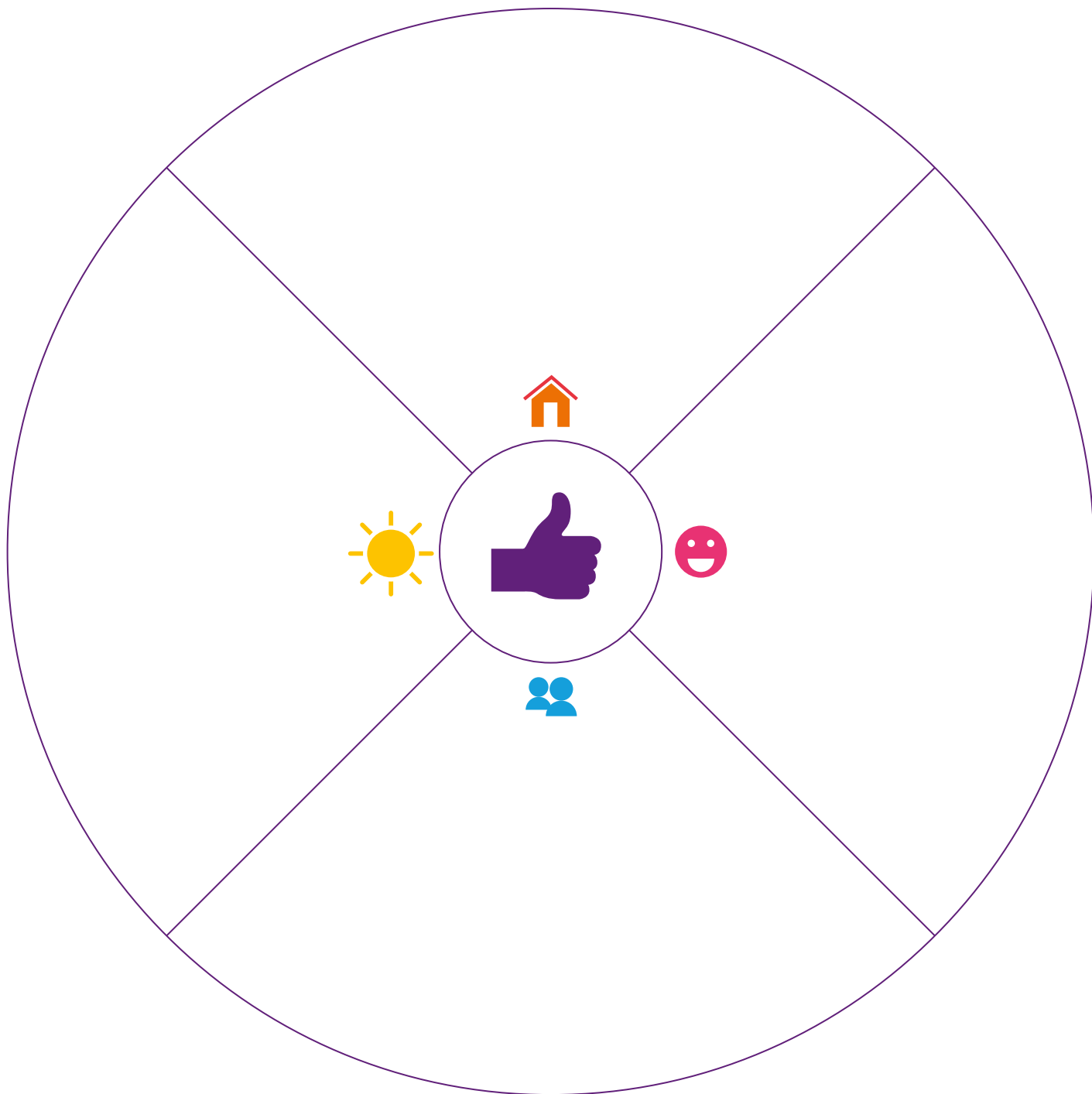
| What is important to and for me | |
|--|---|
|  <p>At home</p> <p>That I have my own space with my favourite things, especially music.</p> |  <p>For my support</p> <p>I have support to live independently at home.</p> |
|  <p>For my health</p> <p>That I know the people who are treating me and that they know me so they can offer the correct support to me.</p> |  <p>For how I feel</p> <p>That I have familiar things things around me and that I feel comfortable in my environment.</p> |
|  <p>For fun</p> <p>Lots of swimming and horse riding.</p> |  <p>To do with friends</p> <p>I have people that I am more comfortable with than others. It's important that I am familiar with the people around me.</p> |
|  <p>For if I want to go to work</p> <p>It must incorporate things that I find fun and it is important that I am supported by someone who knows me very well if I am to go to work.</p> | |

| What is important to and for me | |
|--|---|
|  At home |  For my support |
|  For my health |  For how I feel |
|  For fun |  To do with friends |
|  For if I want to go to work | |

Important to and for me

Example 2



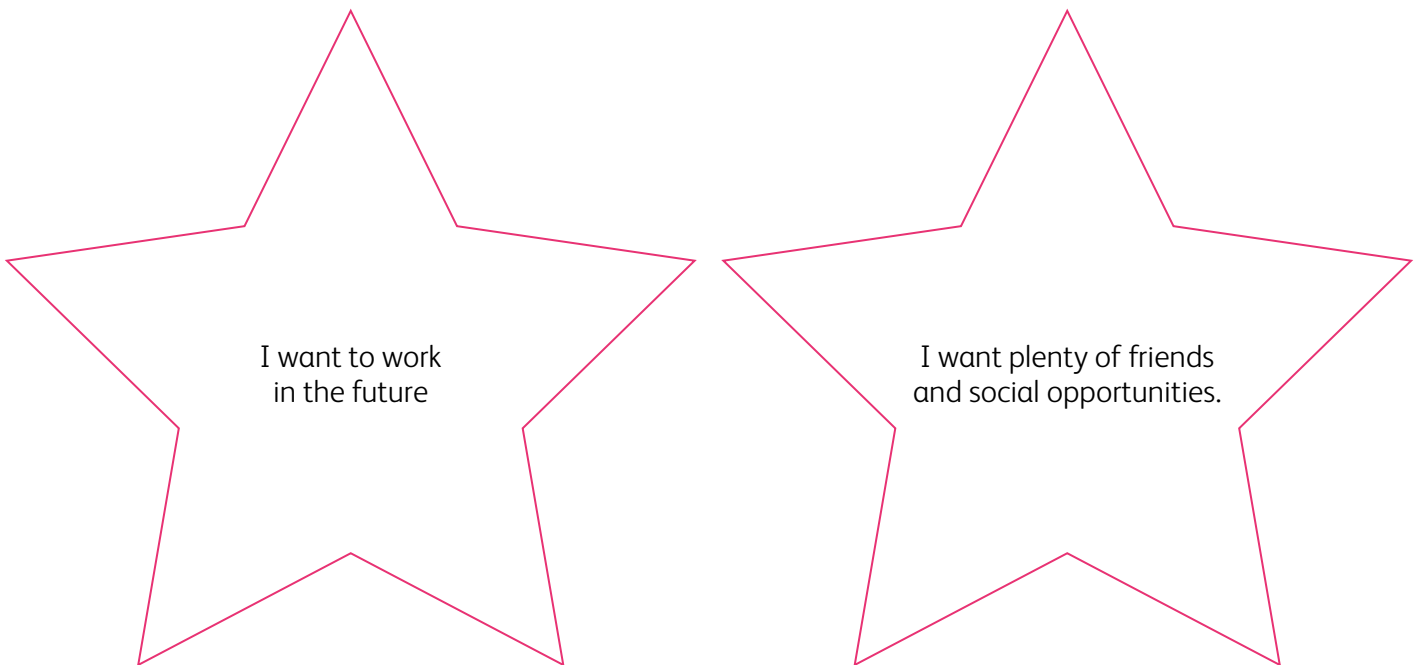


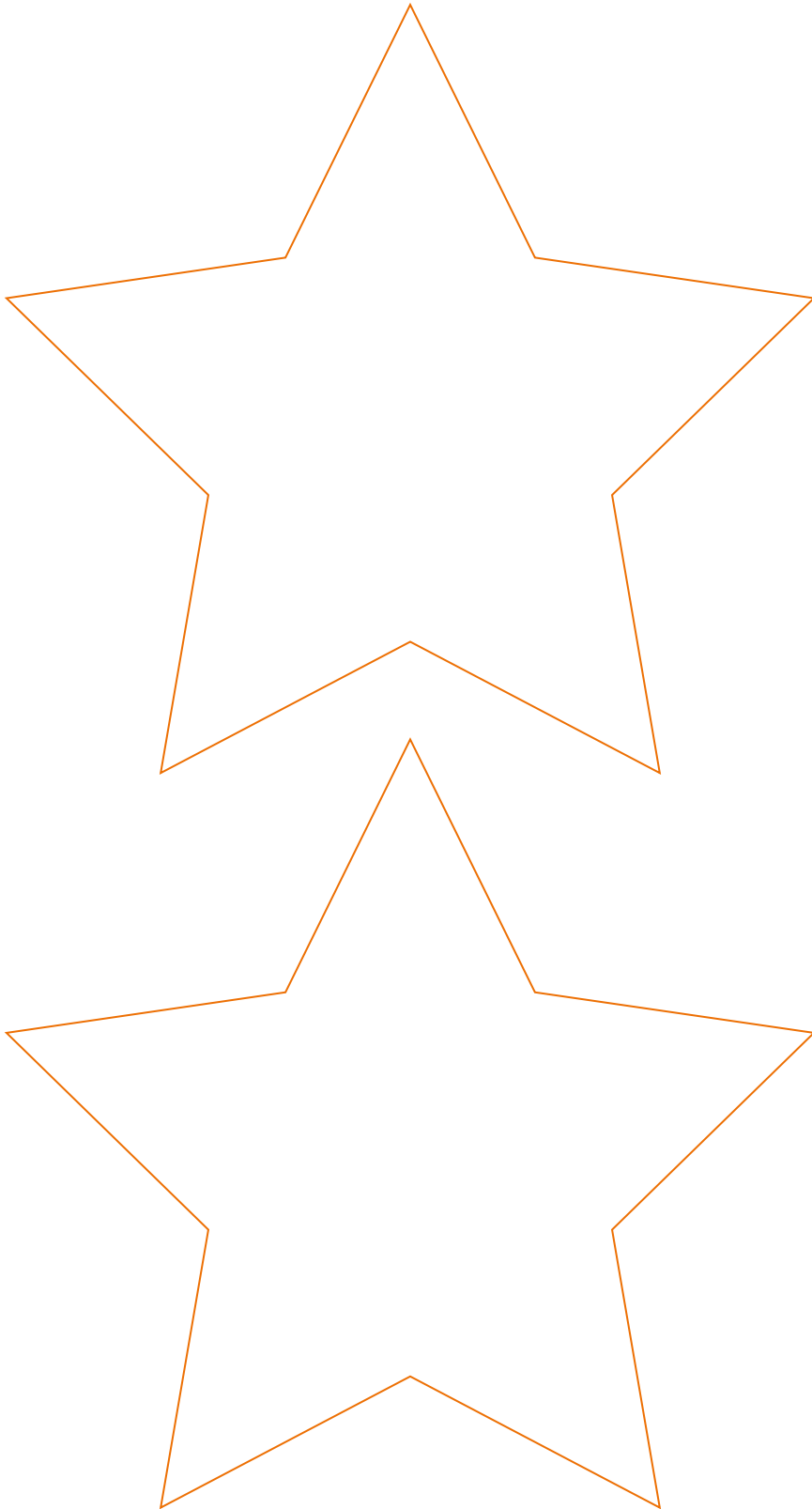
Wish upon a star

This tool encourages disabled people and their families to think about the things they would like to do in the future.

Writing this down or drawing a picture are ways disabled people can share their dreams for the future and help focus support and resources.

Example





How do you feel about....?

Using a Red, Amber, Green system this chart can be used to determine how your loved one feels about different aspects of the future. This can help to focus planning for the future and focus support on areas identified as being particularly important to each individual.

Example

Thinking about the future, look at the different areas and decide how you feel about them.

● **Red:** I'm not happy with it / I need to know lots more about it

● **Orange:** I'm OK with it / I know a little bit about it

● **Green:** I'm happy with it / I know enough about it

Housing



We haven't looked at any options

Care and support



There are lots of professionals involved in my healthcare and this is proving confusing

Finances



I have support to deal with my finances and enough money to pay for the lifestyle I want.

Family, Friends and Community



People help me to experience different activities and to attend a day service

Work



We are not considering this as an option at the moment

Advocacy



I have people I trust to help me make decisions and speak up for my interests

Housing



Care and support



Finances



Family, Friends and Community



Work



Advocacy



Good day/bad day

This tool can be used to determine what a good and bad day look like for your loved one. If you need to, you can base this on observations of how your loved one behaves and their reactions to different people, places and activities.

There are two versions of this tool to choose from – story board or note based. Pick which one is most helpful for you.

Example 1: A good day



Example 1: A good day

| | | | |
|--|--|--|--|
| | | | |
| | | | |

Good day/bad day (continued)

Example 1: A bad day



Example 1: A bad day

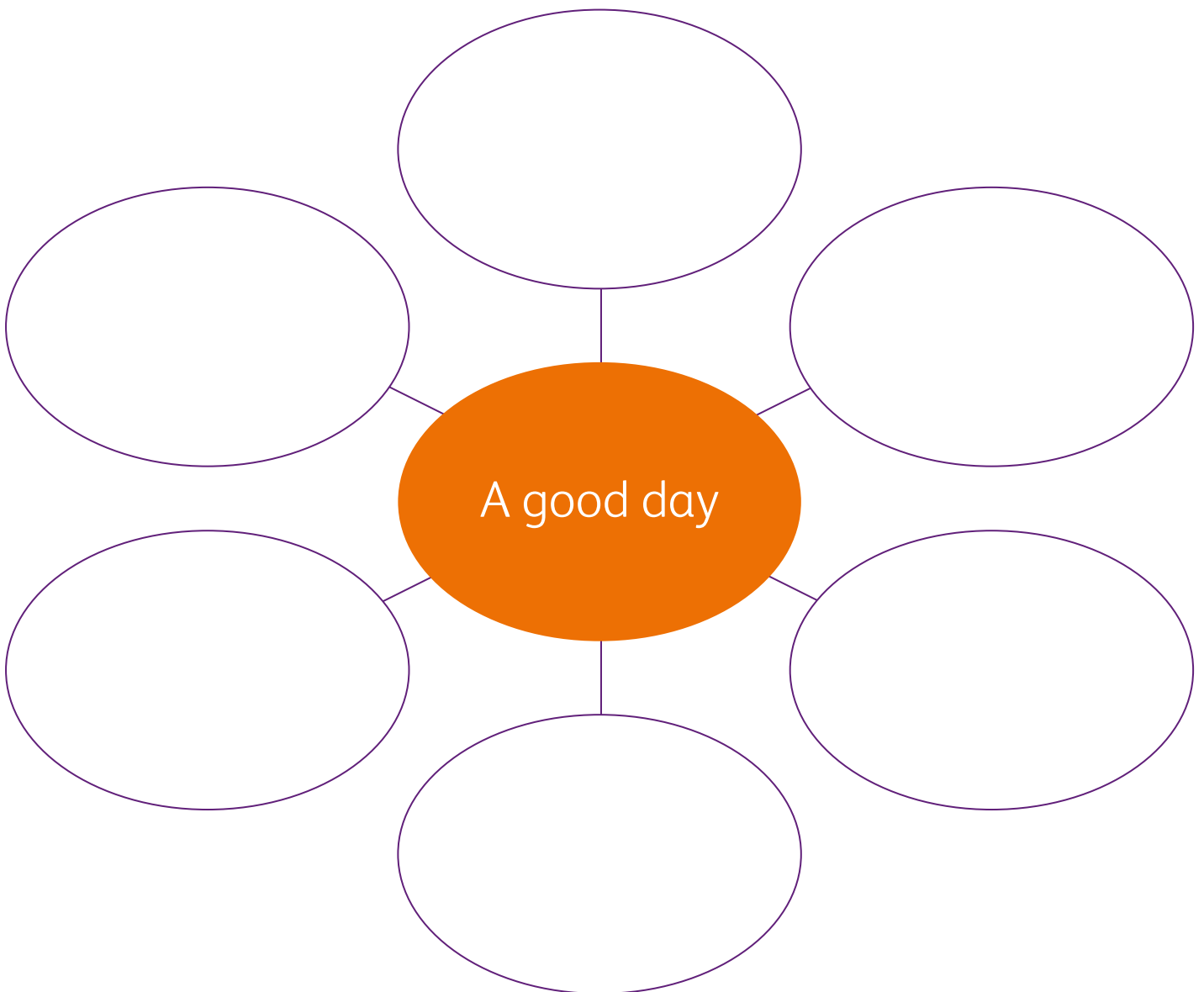
| | | | |
|--|--|--|--|
| | | | |
| | | | |

Good day/bad day (continued)

Example 2: A good day



Example 2: A good day

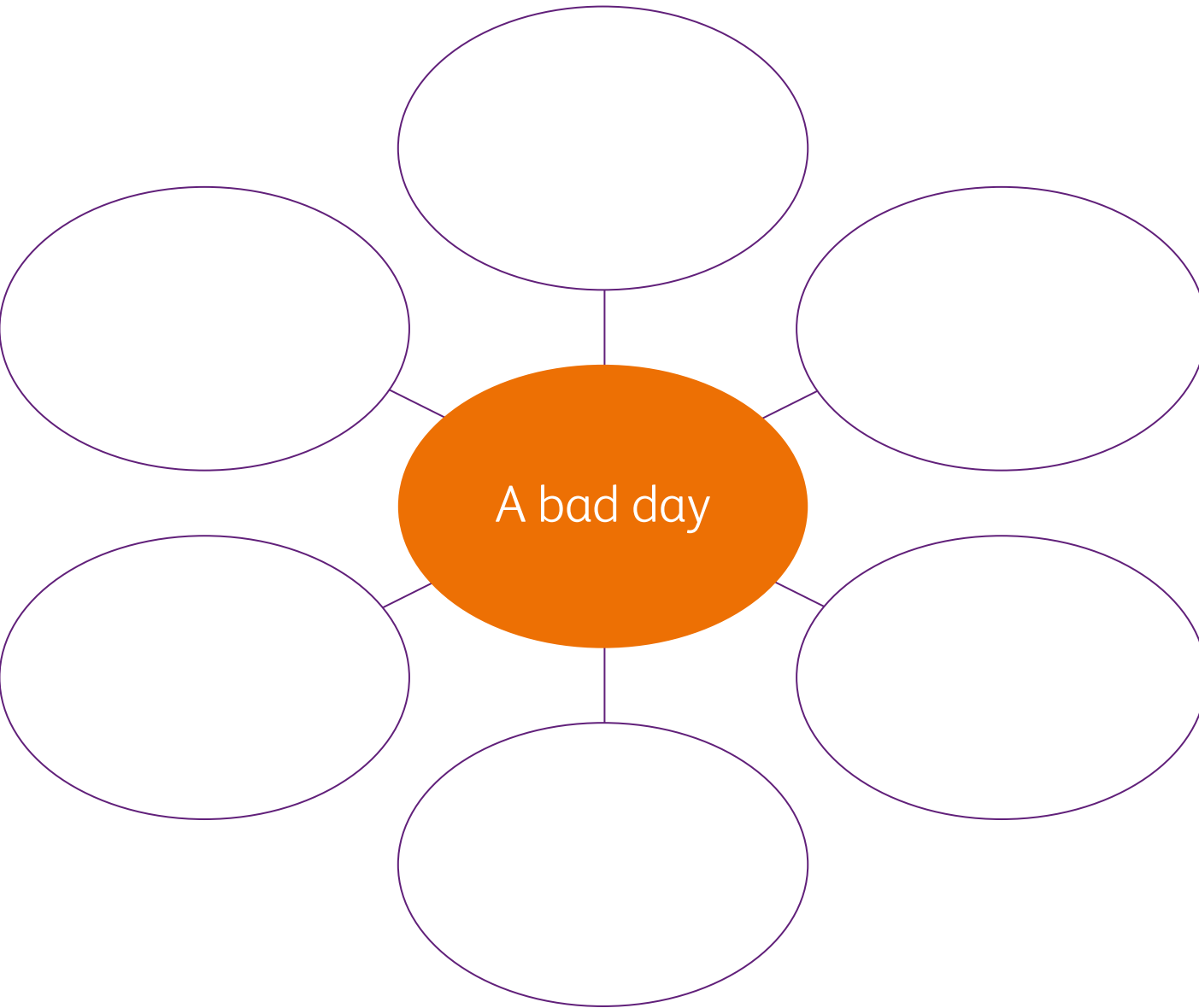


Good day/bad day (continued)

Example 2: A bad day



Example 2: A bad day



Decision making profile

This tool will help you to identify the best way your loved one can be actively involved about choices for the future. You can share this completed profile with professionals so that they understand the best way to involve your loved one in decisions, even if they do not know them well.

The symbol version of the profile (example two) can be used with disabled people who find it easier to read documents supported by symbols. For those with more complex needs you can use experiences, observations and inference to illustrate what decisions would be made by the person.





Example 1

| How I like my information | | | | |
|---|---|--|--|---|
| How I like my information | How to present choice to me | How can you help me understand | When are the best times to ask me to make a decision | When is it not a good time for me to make decisions |
| I require a mixture of objects of reference, tactile cues and practical experience in order to gather information | Give me, or make me aware by moving my hand towards, different objects of reference or tactile cues. I prefer to make decisions on a yes or no basis rather than choosing between two options i.e. give me the object of reference for food and I will either put it on the floor for 'no' or give it to you 'yes'. Then give me the object of reference or tactile cue for drink and I will do the same. This is easier for me than giving me both objects/ cues at the same time and asking me to pick one. | If a decision is more conceptual i.e. choosing an experience/future option then often practical experience is the only way I can make that decision. Music can often be used to motivate me and to help me understand different options for example I have a song that tells me it's time for bed I will then make a choice whether to go to my bedroom or be assisted to go or whether I would prefer to stay where I am. | I struggle if too many things change at once for example if I am in a new place and have new people supporting me I will find it harder to make decisions. | When I am with people who know me then it is easier for my decisions to be interpreted from my behaviour and whether I am comfortable or happy with an experience. If I'm in a new place it may take time for people to be able to understand my behaviour and what that means. |

| How I like my information | | | | |
|---------------------------|-----------------------------|--------------------------------|--|---|
| How I like my information | How to present choice to me | How can you help me understand | When are the best times to ask me to make a decision | When is it not a good time for me to make decisions |
| | | | | |
| | | | | |

Decision making profile (continued)

Example 2

1    
How I like to learn

Objects of reference, practical experience and tactile cues.

2    
How to ask me to choose








Yes or no decisions; offer me a maximum of two objects and I will show my preference by either picking the one I want up or walking towards the one I want. If I decide 'no', it is likely that I will move away or refuse to move towards. Choice apps on the iPad may prove helpful and engaging for me.

3     
How you can help me to understand





Through practical experience and repetition.

4       
When are the best times to ask me to choose?

When I am happy, when I am not tired.





5       
When is it a bad time to ask me to choose?








When I am not around someone familiar, when I am in an unfamiliar environment.

1    
How I like to learn

2    
How to ask me to choose

3     
How you can help me to understand

4      
When are the best times to ask me to choose?

5       
When is it a bad time to ask me to choose?

For more information on these person-centred thinking tools go to:
www.helensandersonassociates.co.uk

About Sense

Sense is a national disability charity that supports people with complex communication needs to be understood, connected and valued. We are here for every person who faces communication barriers in a world that relies on being able to see and hear well to be connected. Our flexible and personalised services empower people to communicate and express themselves – be it through speech or sign, touch or movement, gesture or sound, art or dance. Together, we connect differently and campaign passionately for the right to lead connected and fulfilled lives.

If you, or someone you know, require this information in a different format, please contact Sense Information and Advice - contact details below.

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