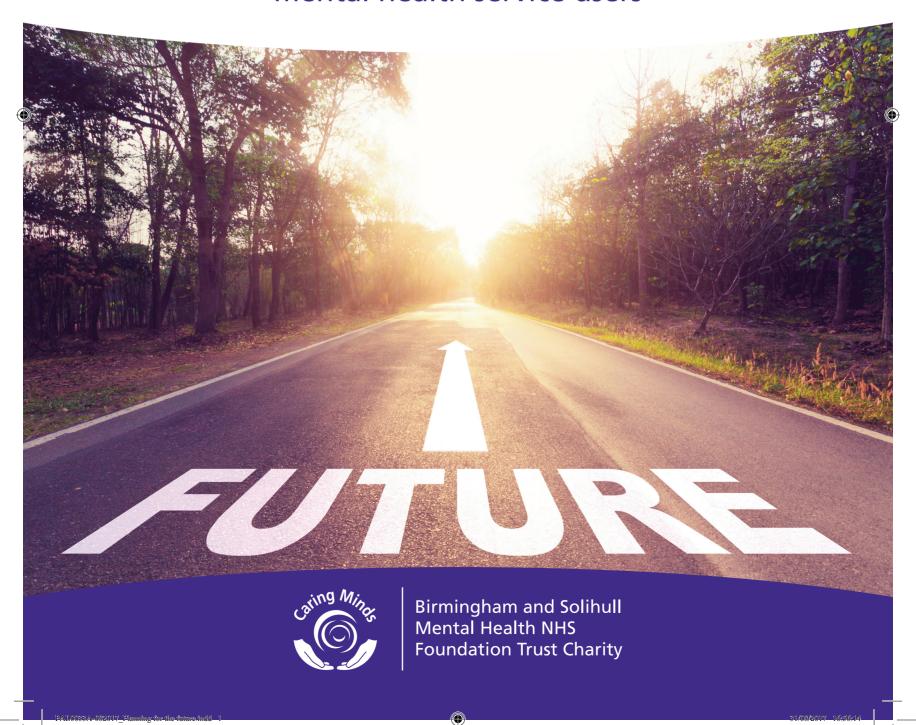




# Planning for the future and emergency planning

A guide for families, carers and friends of mental health service users



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#### **Foreword**

We care for our son who was diagnosed with schizophrenia at the age of 20. Now in his 50's, his condition is stable and we have built up our own style of support with the help of the mental health Trust, mental health charities, The Family Care Trust and MIND. Our son lives in his own home close to us but my wife and I are in our 80's and we feel past our best and are finding it increasingly difficult to meet the demands of caring for our son. Our only relative is our daughter, she lives in London and has two young children so she could not be able to care for our son on a daily basis when we can no longer do so.

We started to worry about what will happen on day one when our son is all alone at home and we are gone or not in a position to help him. We fear his life will become a huge mess in a very short time. This is why we started to develop a contingency plan, which will kick into place when the time comes. All of the organising was a big learning curve for myself and my wife and I felt very strongly that our learning should help others. The learning from our planning has in turn developed into this booklet. It encourages carers to ask all the questions that would allow others to step into your caring role in your absence.

I started thinking about this more than two years ago in relation to my own situation. After a false start but now, with the help of staff from the Trust and a small group of carers, we have produced this booklet. Our aims is to help those caring for someone with a mental illness including dementia, especially where they are concerned about what will happen when they can no longer provide help themselves.

I have been involved for many years with a number of different carers groups. A lot of people have approached me because, like us, they are concerned about what will happen to their loved one when they are no longer able to care for them. Everyone has a situation that is different but we hope this booklet will be of guidance and support to all.

The booklet needs to be shared with family members, including the cared for person, professionals and all those involved. We hope it will provide practical help and support for both yourself and the person you support as well as comfort and peace of mind.

I would like particularly to thank the following people without whose support we would not have been able to produce this piece of work:

Peter Woodhams, Carer
Ann Fitzgerald, Carer
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Sandra Baker, Carer and Family Engagement Lead, BSMHFT
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Natasha Timmins, Support Worker, Stonham Carer Support and Carer
Nicola Emes, Communications and Marketing Department, BSMHFT

Also, all of my fellow carers and family members who have kindly taken the time to proof read and provide feedback on the document and support us along the way.

I would also like to thank John Short, Chief Executive of Birmingham and Solihull Mental Health NHS Foundation Trust and Ali Simpson, Head of Patient Experience and Recovery for their support to get this project started and particular thanks to the BSMHFT Caring Minds Charity for the funding of this project.

Gordon Percival Carer



#### Introduction

The content of this information booklet has been inspired by conversations with families, carers and friends of our service users.

"Once this is done I can put it away safely until we need it." "My wife has dementia, what's going to happen to her if something unexpected happens to me?"

"My husband doesn't like the thought of changes so this will help me to put things in place bit by bit."

"We've always been involved as part of our son's care planning with his clinical team – we want to make sure we are still part of his care by planning in advance in case something happens to us."

"I'm a single mom so this is really important for me to think about – not just for my daughter – my mom and dad rely on me too."

"I just want some peace of mind that he'll be all right in the future when I'm not here to look out for him."

"Having a plan will put my mind at rest."

"A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction, cannot cope without their support."

Carers Trust

If you have picked up this booklet, you may be part of a family or friendship network in which both the carer and the person with mental health issues are very reliant on each other. The person you care for might be your husband, wife, partner, son, daughter, mother, father, sister, brother, cousin, niece or nephew – or you may be a close friend. Whatever your relationship, it's likely that you may have some worries about what the future holds. Even if everyone is managing very well at the moment, you're probably concerned about what happens in the long term or indeed if there is an emergency now.

It is possible in the future that the person caring for a family member or a friend, may no longer be able to do so. The purpose of this booklet is to help carers, families and friends who support someone with mental health issues, by providing them with information that will help with any decisions to ensure continuity of care for the person they support. Planning for the future has no age restriction. There is something in this booklet that may apply to carers of all ages from young carers to those who are caring for someone in their later years.



There are many organisations that are able to support you in preparing for emergencies or planning for the longer term if, as a carer, you are no longer able to support the person you care for. These organisations are listed at the end of this booklet. Some families are able to talk very openly about difficulties they are facing now and their concerns for the future. Others find it much harder, especially if there are different opinions about what might be wanted or needed. Even if it is difficult, it really is important to start talking. You need to think about what is best for both the person with a mental health issue and the main person who is supporting them.

It isn't always easy to start these talks. Raising the issue, and talking about how things may change, can be a real challenge and there are often no easy solutions. However, the more you can do now to ensure that you, the main carer and the person with a mental health issue get the support you need, the more smoothly the future should work out for all of you. The benefit to starting these conversations and putting things in place will be that it is one less thing that as a carer you have to worry about.

As the main carer you are the most important person to work with the person you support, other family and friends, workers and services to prepare for whatever the future holds. Every situation will be different but there will be many core issues applicable to everyone.

It's really important to involve the person you support in any planning about their future wherever possible. Indeed, they may also be worrying about it, even if they haven't raised the issue with you and make sure you take things at a pace that suits both of you.

You shouldn't have to do all of this planning on your own. The more people who know the person you support and whom you can involve in the planning process, the better, including other family members and friends, key workers, social workers, advocates and carer support staff.

#### Information

We have tried to source information from a number of support organisations including those who deal with learning and physical health disabilities as well as mental health. We are unable to recommend any particular service but advise that you contact the organisations listed on pages 20-22 to find out which one can help you best.

# A word about mental health capacity

Capacity to make decisions when related to the future planning process can apply to either the service user in understanding the decisions being made or to the person who provides the support being able to make decisions in the future.

The Mental Capacity Act aims to empower and protect people who may not be able to make some decisions for themselves. It also enables people to plan ahead in case they are unable to make important decisions for themselves in the future. A lack of mental capacity could be due to:

- a stroke or brain injury
- a mental health problem
- dementia
- a learning disability
- confusion, drowsiness or unconsciousness because of an illness
- substance or alcohol misuse.

If you have any concerns about capacity either for yourself or the person you support, please contact one of the support agencies listed on pages 20-22 for advice before you start the planning process.



## How to start the planning process...



Carers sometimes say they feel it is unfair to involve other people in decision-making as they think the responsibility sits with them and the person they support. However, often wider family and friends are willing to be involved and often appreciate being asked as they can see things from a different point of view. It may be that the person you support already has quite a few people involved in their lives, so it is not difficult to decide whom you might ask for support. As with all planning and decision making, the

person you support should always be involved and have a say in how they would like to plan and who they would like to support them. If you think they would find this subject difficult, you can think about what needs to be put in place and try out different ways of making them feel at the centre of what is going on.

## Some tips to help you plan

Discussing planning for the future can be a really difficult conversation for some people. These are some tips that may help you:

#### 1. Pick the right setting

Choose a time that works for both of you and a place where the other person is likely to be comfortable and therefore more receptive. At the beginning of the planning stage, it may be better to have the conversation between the two of you. Only involve other people at this point that the person you support feels comfortable with – this may be another relative or a friend or a support worker. Let them lead as much as possible: choosing who they would like to plan with, where and when to plan, and doing it at a speed that works for them.

#### 2. Acknowledge your own anxiety about the conversation

Try to focus on what you hope to gain from the conversation rather than the challenge of it. You could possibly start the conversation by saying something simple such as "This conversation has been on my mind, and I don't want to upset you, but it might be useful to both of us". This may break the ice a bit and help both of you to let down your guard.

#### 3. Plan what you need to say

Make a list of what you want to discuss and what is a priority. You could use the checklist included in this booklet to help prompt you (pages 16-18). Make sure the discussion is directed by the person you support rather than around them (i.e. not talking about them in the third person).



#### 4. Listen as much as talk

Make sure that you give the person you support space to talk and express their wishes and make it a conversation between you rather than a question and answer session. Give them space to think through their own ideas about the future and support to say what they think – sometimes this may not be what you are expecting to hear.



### Things to consider

#### How to discuss it with the person you support

- Who is currently in your relative/friend's life and how does your relative see their involvement in the future?
- What are the things that are most important to your relative? For example, this could be their home, social life, the security of regular routines etc.
- How does the person you care for need to be supported to ensure they are safe and well and able to continue with their day-to-day life?



- What concerns you (as the main person providing support) most? For instance, are you worried that
  your relative will get into financial difficulty, lonely, or lose contact with their friends or other support
  networks.
- For emergency planning, ask the person you support who they would like to be contacted straight away to support them.
- Ask friends or family members whether they can or are prepared to help? This can be quite a big commitment to ask a family member or friend so please check that they are willing and able to take on any responsibility. Make sure you are absolutely clear what they can take on if you are unable to support the person you care for.



What sort of support is absolutely essential to the person you support, for instance, with health needs, travelling, or money matters? This could extend to health test arrangements, form filling, benefits, etc.

#### Who should the plan be shared with? Where? How? When?

- Where will the plan be kept? How many people will need a copy of the plan? Will the plan contain confidential information that needs to be kept private by the person looking after it?
- When will the plan be reviewed? Remember that if you are planning in advance to keep your plan updated of any major changes, for example, contact details (name and addresses). It might be worth checking for changes every six months.
- Raise the issue with mental health services. This can be with your relative's care co-ordinator or key worker in the first instance. The best way to do this is to make an appointment and go with the person you support with you if possible. Please ensure that the care co-ordinator understands that the plan needs to be recorded on the medical records system of the person you support and also on your carer's record if you have one. If your relative is under the care of the GP then discuss it directly with your GP surgery and similarly ensure that the plan is on the GP medical records system for reference.





Think about welfare benefits, power of attorney, guardianship, wills and trusts.

Will there be a need to provide advocacy to protect the rights of the person you support? It may be helpful for you to use the services of an advocacy service when you are having planning discussions with your relative/friend. The advocate can be involved to act on your relative/friend's behalf and this will ensure that their wishes are taken into account when planning ahead. For example, they can:

What practical, legal and financial arrangements need to be made

- listen to the service user's views and concerns
- help them explore their options and rights (without advising them in any particular direction)
- give them information to help them make informed decisions.

An advocate will also be able to support your relative or friend independently, which may provide you with extra reassurance that your relative/friend's opinions are being taken into consideration.

#### Remember

Please remember to get written consent from all parties involved in your future planning before sharing the information with anyone.





## Help with planning

## If you start finding it hard to care for your relative

You can ask for a carer's assessment from your local council or social services department. A carer's assessment is available to carers who provide, or are intending to provide, regular and substantial care to a relative or friend. You have a legal right to an assessment of your own needs. It is not an assessment of your ability to be a carer, but whether you need any support to help you care for the person and maintain your life outside of caring. During a carer's assessment you will have an opportunity to discuss the support available and agree a care plan for yourself that addresses your needs.



You are entitled to a carer's assessment even if the person you are caring for does not want to receive services. Carer's assessments are available in partnership with the service user or separately. If you haven't had a carer's assessment, please contact your local mental health team services or your local social services team.

When you have your carer's assessment, planning for unexpected events and emergencies should be included. If it is not covered, please ask about this. If you have already had a carer's assessment and planning for an emergency was not covered, please contact the organisation who completed your assessment so that his information can be added.

## How the Care Act can help families when planning for the future

The Care Act 2014 replaces a number of previous laws and good practice guidance and aims to simplify the framework for providing care and support. Personalisation (personal needs) as well as choice and control are central in the act. Most of the changes came into effect in April 2015. In relation to planning for the future, applying the principle of wellbeing could mean that during an assessment it is identified that putting things in place for the future would contribute to your relative's wellbeing (and yours, as a family carer).

#### Information

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Most of the support agencies listed on pages 20-22 will be able to give you advice about the Care Act.

Factsheets are also available at www.gov.uk

Under the Care Act, local authorities have an increased duty to provide information and advice to make it easier for people to make well-informed choices about their care and support.

Information and advice is to be provided at times when people need it and should include general details about the way the system works as well as more personalised information about support available for individuals, this will include physical as well as mental health wellbeing.

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## **Making financial plans**

Making decisions about leaving your money and possessions (assets) is an important part of planning for the future. If you are able to leave something for the person you care for, this could provide them with additional choices and flexibility in their life and enable them to spend money on things as their needs change.

This should be done in a way that will be recognised in law rather than relying on a friend or relative to informally put it in place.

## Finding a solicitor

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The advice of a solicitor may be helpful if you are wishing to put in place more formal financial arrangements for the person you support. Finding a solicitor who has experience and knowledge of drawing up wills and setting up trusts for families with dependent relatives could make it easier for you to explain what you need. You must make sure that you ask for an estimate of the cost of any services beforehand in writing.

#### Information

This booklet can only provide an overview of things that you may wish to consider. For more formal advice please see pages 20-22 for a list of organisations that may be able to help you further.

The Money Advice Service is a free and impartial advice organisation set up by the Government, they can provide advice over the phone or online. Contact 0800 138 777 or www.moneyadviceservice.org.uk.

#### Information

Further information on legal matters and useful factsheets can be obtained from www.mind.org.uk/information or www.rethink.org/resources



#### Financial advisors

Financial advisors are professionals who offer advice on financial matters to their clients and recommend suitable financial products. Some advisors can offer the full range of financial products and providers available, and are called independent advisors. But many advisors have chosen to offer restricted advice and will focus on a limited selection of products and/or providers.

#### Information

Further information can be obtained from the Financial Conduct Authority on 0800 111 6768 or www.fca.org.

All financial advisors have to be approved or authorised by the Financial Conduct Authority. Both independent and restricted advisors must pass the same qualifications and meet the same requirements to ensure they are providing suitable advice.

An advisor or firm has to tell you in writing whether they offer independent or restricted advice, but if you are not sure what they offer you should ask for more information. It is important that you ask what services a financial advisor can offer so you know they are able to offer the right services for you. You should also be asking what fees and charges you may have to pay for the advice. There may be a charge for the initial consultation whether or not you decide to continue with the service.

## Appointeeship and suitable persons

If a person has been assessed as lacking capacity to manage their money and receives benefits, the Department for Work and Pensions (DWP) can appoint someone to take responsibility for managing this income. If you are the appointee for your relative, you should think about who would take over this role should you no longer be able to carry out your responsibilities (which are to sign claim forms, notify the DWP about any changes affecting how much your relative can claim, ensure the money is spent in their best interests and to notify the DWP if you stop being appointee.

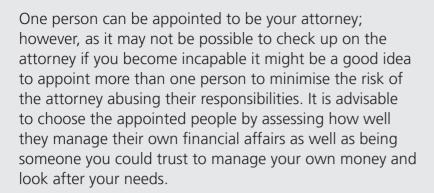
## Lasting power of attorney

A lasting power of attorney (LPA) in England and Wales is a document, which allows someone to appoint a person they trust to act as an attorney and make decisions on their behalf, if necessary.

A lasting power of attornery can be drawn up at any time while the person still has capacity but it will not be deemed as being legal until it has been registered with the Office of the Public Guardian.

Once the lasting power of attorney has been registered it can be used at any time whether the person still has the mental ability to act for themselves or not.

There are two different types of lasting power of attorney documents that can be drawn up. The first is called a Property and Affairs LPA, which allows the appointed person to make decisions about how your money is spent and the way your property and other affairs are managed. The second is a Personal Welfare LPA, which allows the appointed person to make decisions about your healthcare and general welfare including refusal of medical treatment and deciding where you live. These decisions can only be made by the appointed person after your LPA has been registered and you lose the ability to make the decisions yourself.



#### Information

For more information please see our useful contacts on pages 20-22.

Useful websites are www.gov.uk or the NHS Choices website at www.nhs.uk.

The person making the LPA may include a restriction that the LPA can only be used at a time in the future when they lack the capacity to make decisions for themselves for example, due to the onset of dementia in later life or as a result of a brain injury.

An attorney will not be able to make decisions about a person's personal welfare unless they have also been appointed as a Personal Welfare Attorney using a separate LPA.

A Personal Welfare LPA can only be used when the person making it lacks the capacity to make these decisions for themselves.

## Discretionary trusts

A discretionary trust can be used to ensure money, property or investments are protected so that they are still available for your relative. It involves the legal transfer of the assets to trustees who then have a discretion (choice) as to how to deal with these assets. The discretionary trust would need to name more than one beneficiary, but this can be achieved by naming a group of people that would include your relative. Trustees decide which of the beneficiaries receives help from the trust using the guidance you have left in your letter of wishes (it is important to choose trustees whom you believe will respect your wishes).

Discretionary trusts are worth considering because they can be used as a way to:

- leave an inheritance to the person you support
- set up a group of people to manage your assets (money or property) for the person you support
- prevent the person you support from losing means-tested benefits and
- care funding from being stopped.

There are two ways of using a discretionary trust:

- to own, manage and look after a property
- to give money that can be used to pay for things that would not otherwise be affordable for the person you support.

For both purposes, the trust can be set up to be used in your lifetime or in your will for your relative to inherit after your death.

#### Information

For more information please see our useful contacts on pages 20-22.



## **Emergency planning**

Emergency plans are not just for carers who live with the person that they support, they can be equally useful if the person you care for lives in their own home and you are part of their support network.

Having a written emergency plan is important as it can prevent an emergency becoming a crisis. As a carer, you are the expert in the care you provide to someone. If something happens to you, that knowledge needs to

#### Remember

Please remember to get written consent from all parties involved in your emergency plan before sharing information with anyone.

be available to others. By planning in advance, with the hope that the plan never has to be used, you can share your knowledge and allow someone else to be able to step into your caring role. This reduces anxiety for you and the person you care for should an emergency occur. Planning also allows you to have conversations with family, friends and neighbours about the role they could play in an emergency.

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## **Useful checklists**

The following pages contain some ideas of things you may want to start to think about. There are blank pages for your own lists.

## Example checklist

What is in place now for the person I support?	What may need to be put in place for the future?	To do	
	Medical		
Going to appointments – mental health, GP, dental, etc. I remind them to go.	Text reminders. Support worker to remind.	Find out from each service what they are able to support.	
Physical health checks	Reminders for blood pressure, BMI, eye tests.	Speak to clinical team and/or GP or practice nurse.	
Reminder to take medication	Discuss with person you support, clinical team or other friends/family members.	Ensure that clinical team are made aware of any new arrangements.	
	Practical		
Where do they live now?	Supported housing or residential care.	Discuss with the person where and how they would like to live. Ensure social worker or support worker is involved if appropriate.	
Reading letters and filling in forms	How is this done at the moment? Can the person manage this themselves?	Discuss with person about an advocacy services to help them. Is there a relative or friend to help?	
Getting money	Day-to-day budgeting of finances. Help with benefits or bank accounts. Managing any credit.	Discuss options with social worker or support worker.	
Paying bills	How are bills paid at the moment? Is this working ok? Do they come through the post or online? Consider how meter readings are done.	Consider water meters/smart meters. Speak to utility companies about options for payments.	
	Social		
Keeping busy and active	What does the person enjoy doing at the moment? What needs to continue? Where does the person get information about activities from?	How will this continue? Who can help?	
Social needs/meeting friends or going to groups	How will the person access groups? How will they get to the group? Are they happy to go on their own?	Explore transport options if needed. Discuss with the person what they would like to happen. Is there a volunteer befriending service to help?	





What is in place now for the person I support?	What may need to be put in place for the future?	To do
	Home	
Home maintenance	Who currently looks after the property if applicable? Can the home be inspected for safety issues? Possibly consider home insurance.	Speak to housing provider for information. Ensure there is a list of contacts for emergencies such as water leaks, boiler breakdowns, etc.
Keeping the home tidy and clean	How will this be done? Can the person do this themselves?	Options for employing a cleaner/ housekeeper. How would this be paid? Can family or friends help?
Washing clothes	How will this be done? Can the person do this themselves?	Discuss with the person what they would like to happen.
Cooking meals	How will this be done? Can the person do this themselves?	Discuss with the person what they would like to happen.
Do they have a car?	If yes, can they maintain it? If no, can arrangements be made, such as:  • bus pass  • taxi Service  • other friend or relative for lifts.	





## Write your own checklist

What is in place now for the person I support?	What may need to be put in place for the future?	To do



What is in place now for the person I support?	What may need to be put in place for the future?	To do







Notes



## Information and support services

## Useful contact details for further information and advice

Every attempt has been made to check the veracity of the information linked to, we do not monitor the content of third-party websites and do not accept any responsibility for any third-party website.

The hub offers a wide range of services including Information, advice and support to people who care for friends and family with disabilities. Includes free advice on welfare benefits, form filling, one-to-one appointments on request, assistance to help carers to access grants, social services, equipment, finance, care homes, home care, holidays and leisure.  Appointments available at the anyone of the four Birmingham City Council Centres and by referrals from the GP surgeries.
CERS is a FREE emergency back-up service to provide support to those caring for a dependent family member, neighbour or friend living in Birmingham. Once registered, a highly trained team member will assess your caring situation and agree an emergency back-up plan. You'll receive a dedicated emergency contact number for times of crisis so CERS can spring into action when you need them most. They can provide support for up to 48 hours (72 hours on bank holidays), after which, longer term care can be arranged if necessary.
Our mental health carer support service offers information and advice to carers of people with mental health needs in Birmingham.  Support service includes:  • information, advice and signposting  • one-to-one support with bespoke support plans  • large variety of facilitated peer support groups  • family support worker(s)  • support line for Birmingham Carers, 8am to 8pm, Monday to Friday  • bimonthly service-led steering group  • monthly carers information pack.
0121 303 1234 www.mycareinbirmingham.org.uk
Information Helpline: 0344 477 1010 9.30am to 4.30pm, Monday to Friday Deaf/Hard HearingTextphone Adviceline Number: 18001

0344 411 1445

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#### Solihull area services

Solihull Carers Hub and Solihull Young Carers  0121 788 1143 www.solihullcarers.org	Solihull Carers Centre offers a telephone support line which includes emotional support, advice and information and signposting to additional organisations. They also carry out carers assessments and reviews.  Solihull Young Carers offers one-to-one support, advice, help to find other services that can support young carers. The Young Adult Carers Team is a new service which offers activities, training, advice and guidance to Young Adult Carers aged 18-25 years. We provide free and confidential information, advice and guidance, as well as holding one to one and group support sessions.
Solihull Social Care	0121 704 8007 connectcc@solihull.gov.uk www.solihull.gov.uk
Citizens Advice Bureau (Solihull)	Local: 0121 704 7810 10am to 2.30pm, Monday to Friday National: 03444 111 444 10am to 4pm, Monday to Friday www.casb.org.uk
Solihull Mind	0121 742 4941 contact@solihullmind.org.uk www.solihullmind.org.uk
Family Care Trust (Solihull only)	0121 770 1578 enquiries@familycaretrust.co.uk www.familycaretrust.co.uk

## Advocacy services

POhWER Advocacy	0300 456 2370 www.pohwer.net/birmingham	
Voiceability Independent Care Act Advocacy	0121 222 6327 www.voiceability.org/birmingham	
Solihull Advocacy	0121 706 4696 office@solihulladvocacy.org.uk www.solihulladvocacy.org.uk	

## Bereavement services

Cruse Birmingham Support for bereaved people of all ages	Helpline: 0121 687 8010 www.crusebereavementcare.org.uk
Solihull Bereavement Counselling Service A service for people living and working in Solihull	0121 424 5103 9.30am to 4.30pm, Monday to Friday www.solihullbereavement.org



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#### Financial advice

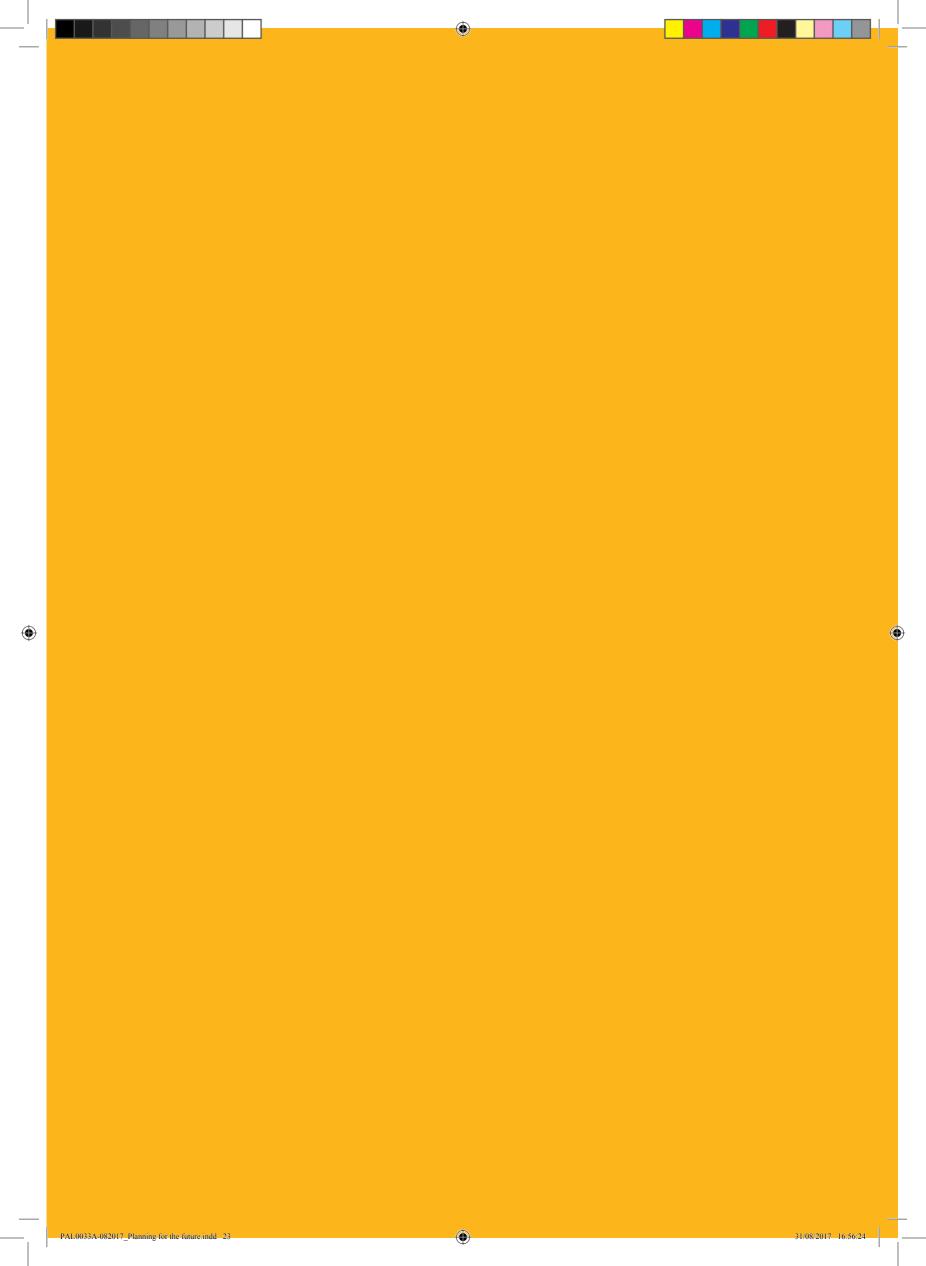
Please note this is an example of services available and there are a number of other recommended services, please contact your local citizens advice service or local carers advice centre for further information.

Mencap Wills and trusts service	0207 696 6925 www.mencap.org.uk/willsandtrusts
Penderels Trust Trust funds and financial planning information)	0845 0500 862 enquires@penderelstrust.org.uk www.penderelstrust.org.uk
Money Advice Service	0800 138 7777 www.moneyadviceservice.org.uk
Office of the Public Guardian	PO Box 16185 Birmingham B2 2WH customerservices@publicguardian.gsi.gov.uk 0300 456 0300
Society of Later Life Advisers (SOLLA)	0333 2020 454 admin@societyoflaterlifeadvisers.co.uk
Rethink Trust Corporation (Discretionary trusts)	0300 222 5702 rtc@rethink.org www.rethink.org

## National helpline contacts

Rethink Mental Illness Advice Service	0300 5000 927 9.30am to 4pm, Monday to Friday advice@rethink.org www.rethink.org
Carers Uk	0808 808 7777 advice@carersuk.org www.carersuk.org
Mental Health Foundation	020 7803 1100 info@mental health.org.uk www.mentalhealth.org.uk
Alzheimers Society	0800 222 11 22 www.alzheimers.org.uk
Dementia UK	0800 888 6678 www.dementiauk.org
Age UK	0800 169 6565 www.ageuk.org.uk
Carers Trust	0844 800 4361 www.carers.org

Lesbian, gay, bisexual and transgender (LGBT) people with mental health issues, and their carers, partners, friends and relatives, may be anxious about accessing services due to fears of homophobia or of not having their specific needs met. All of the contacts listed will have access to specialised LGBT information or be able to signpost you to other appropriate support agencies.





www.bsmhft.nhs.uk Main switchboard: 0121 301 0000