

Supervised by:  
Neil Allen  
Kirsty Keywood

# How to Guides

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## Dementia and Carers



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# Introduction: Health and Social Care Divide (I)

There is help and support available for families living with dementia from both the NHS and your local council. Your local council can arrange social services, such as washing and dressing, meals and access to day centres, under the provisions of the Care Act 2014.

However, these services are means-tested. In other words, the person you are caring for may have to pay for the whole or part of the services, depending on their financial situation.

# Introduction:

## Health and Social Care Divide (II)

The NHS, on the other hand, offers medical treatment and funding for healthcare and social care services under the provisions of the NHS Act 2006. The funding provided by the NHS includes Continuing Healthcare (CHC) and funded nursing care (FNC) and is based purely on needs.

The health and social care schemes are distinct but overlap. From a practical perspective, NHS funding is the preferred option, as it is not means-tested. In a relatively small number of cases, a person's care needs are such that the local authority is not permitted to meet their ongoing care needs and they become the full responsibility of the NHS through CHC funding.



# How to apply for NHS Continuing Healthcare and NHS-funded Nursing Care

# Overview of CHC

CHC is a package of ongoing care that is arranged and funded solely by the NHS. Such care is provided to an individual aged 18 or over, to meet health and associated social care needs that have arisen as a result of disability, accident or illness.

This means that the NHS may cover the entire cost of the care a person with dementia receives, including the services provided by the local council.

However, the person you are caring for will not automatically qualify for CHC following a dementia diagnosis; instead, they must have complex health and care needs.

To be eligible for CHC, the person you are caring for must be assessed and found to have a primary health need.

# Introduction to Primary Health Need

According to the National Framework for CHC and FNC, the concept of primary health need is central to determining whether a person is eligible for CHC funding.

Available at:

<https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>



## a) Health and social care needs (I)

It is useful to first articulate the meaning of health and social care needs.

Although there is no legal definition of a health need, in general terms it can be said that such a need is one related to the treatment, control, management or prevention of a disease, illness, injury or disability, and the care or aftercare of a person with these needs.

Likewise, a social care need is not defined in law, but the National Framework equates the term with the national eligibility criteria for care and support introduced by the Care Act 2014, s 13.

There are three conditions.



# a) Health and social care needs (II)

1. An individual's care needs must arise from or relate to a physical or mental impairment or illness (including dementia).

2. The person's needs mean that they cannot do at least two of the following:

- Managing or maintaining nutrition
- Maintaining personal hygiene
- Managing toilet needs
- Being appropriately clothed
- Being able to make use of their home safely
- Maintaining a habitable home environment
- Developing and maintaining family or other personal relationships
- Accessing and engaging in work, training, education or volunteering
- Making use of necessary facilities or services in the local community
- Carrying out any caring responsibilities

## a) Health and social care needs (III)

3. Third, there is, or is likely to be, a significant impact on the person's wellbeing as a result of not being able to do those things.



## **b) Primary health need (I)**

In assessing whether the person you care for has a primary health need, all their needs are taken into account. A person will have a primary health need, if the majority part of the care they require is focused on addressing and/or preventing health needs.

Whether someone has a primary health need does not depend on a specific health condition or diagnosis, nor on who provides the care or where the care is provided. Rather, it is about the level and type of an individual's day-to-day care needs taken in their totality.

## b) Primary health need (II)

The primary health need test involves both quantitative and qualitative considerations. Indeed, the National Framework lays down four key indicators:

### 1. Nature:

This describes the characteristics and type of an individual's needs and the overall effect these needs have on the individual, including the type of interventions required to manage those needs.

### 2. Intensity:

This concerns the extent and severity of the needs and the support required to meet them, including the need for sustained/ongoing care.

## **b) Primary health need (III)**

### **3. Complexity:**

This factor is about how the individual's needs present and interact and the level of skill required to monitor the symptoms, treat the condition and/or manage the care.

### **4. Unpredictability:**

This describes the extent to which an individual's needs changes and thus create challenges in managing them, including the risk to the individual's health if adequate and timely care is not provided.

## **b) Primary health need (IV)**

A Clinical Commissioning Group will decide on a person's eligibility for CHC, based on their assessed needs.

It should be noted that eligibility for CHC is not indefinite and is subject to review, as needs may change. For the same reason, just because a person with dementia is not eligible for CHC at one point, it does not mean they will not qualify for CHC at later stages— given that dementia is a progressive/deteriorating condition.

# Assessments

The assessment will ordinarily take two stages.

The assessment will ordinarily take two stages. First, a checklist screening carried out by a qualified professional is undertaken. This is followed by a full assessment referred to as multidisciplinary team (MDT) assessment alongside the Decision Support Tool (DST) assessment.

In exceptional health circumstances, individuals could qualify for Fast-Track, which automatically exempts them from the assessment test to be considered for CHC Funding.

## What would the assessment entail? (I)

The MDT carries out a full assessment for NHS continuing healthcare. The core purpose of the MDT is to make a recommendation on eligibility for NHS Continuing Healthcare drawing on multidisciplinary assessment of needs.

The assessment will be undertaken by a team consisting of at least two professionals from different healthcare professions (GP, consultant, community mental health nurse) and one social care professional qualified in assessing people for care services.

Ultimately, the MDT works together to collate and review relevant information surrounding the individual's needs to ensure this is correctly reflected in their recommendation.



## What would the assessment entail? (II)

In considering individual needs, their interests are considered alongside professional views. These include opinions and health concerns taken into consideration in determining their eligibility.

## Decision Support Tool (“DST”) (I)

The assessment of eligibility for continuing healthcare using the decision support tool will primarily focus on consistent decision making, complementing practitioners in the MDT.

## Decision Support Tool (“DST”) (II)

Alongside the MDT, the DST aims to consider a holistic range of factors and to provide practitioners with a method of bringing together and recording various needs in 12 “care domains” of generic areas of needs.

A completion of the DST will ordinarily result in an “overview” of the individual’s needs encapsulating the nature, complexity, intensity and unpredictability of their respective needs and balancing the interest between quality and quantity of care needed to meet those needs.

The figure in the next page illustrates an example of the domains themselves and the nature of needs. From lowest to highest priority (“P”).

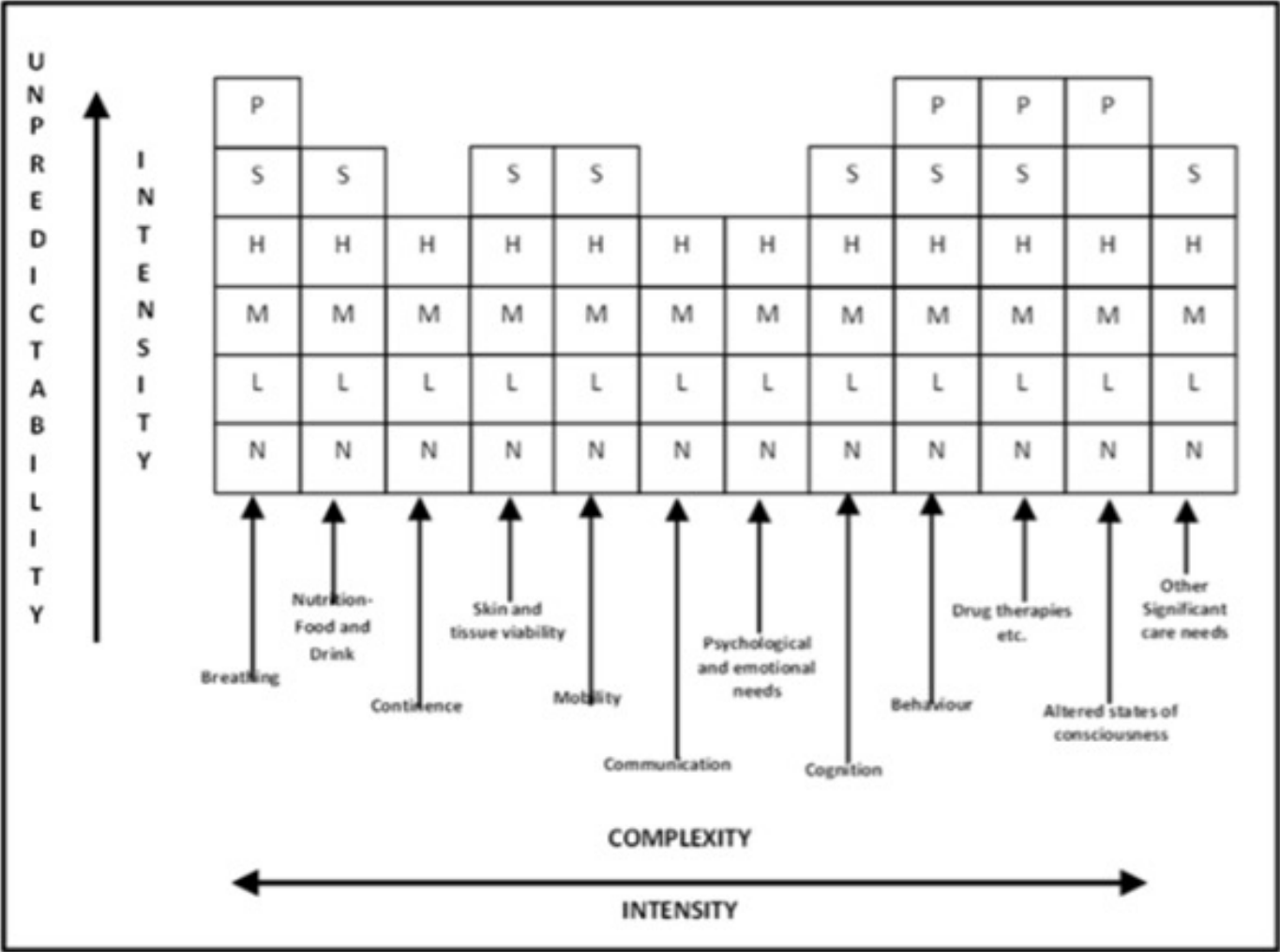
## Decision Support Tool (“DST”) (III)

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# Decision Support Tool (“DST”) (IV)

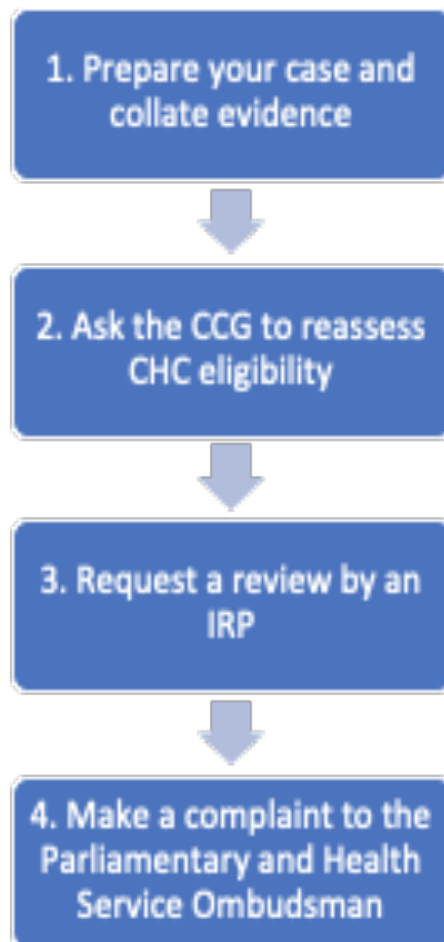


# Appeals

If you are unhappy with the assessment decision, you may wish to appeal and can follow the four steps as summarised by the Alzheimer's Society.

Available at:

[https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/when\\_does\\_the\\_nhs\\_pay\\_for\\_care.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/when_does_the_nhs_pay_for_care.pdf)



# How to challenge the CHC eligibility decision made by the CCG in 4 steps

## 1. You should prepare your case.

Before you formally challenge the decision made by the CCG, you must ensure you have grounds or specific reasons to do so.

To that end, you should get a copy of the completed DST and ask the CCG to explain their decision-making process.

You may also want to collate other documentary evidence, such as the care needs portrayal and social services, care home and NHS patients records.

# How to challenge the CHC eligibility decision made by the CCG in 4 steps

2. You should ask the CCG to review your case.

Importantly, you must write to the CCG within 6 months of receiving their decision and tell them that you want a review of the assessment. The CCG has 5 working days to acknowledge receipt of your request and provide you with necessary information on the appeal process in writing.

The CCG must then launch a review and make another eligibility decision within 3 months of receiving your request.

# How to challenge the CHC eligibility decision made by the CCG in 4 steps

3. You may request a review by an independent review panel (IRP), if you feel the CCG has not correctly applied the DST or has not followed the proper procedures.

To do so, you need to write to NHS England to state you are unhappy with the CCG's decision and to request an independent review. In your letter, you should explain why you disagree with the CCG's decision. If NHS England decides to convene an IRP, the IRP will talk to all of the people involved in the case (including the person with dementia, the health and social services staff and other relevant parties) and examine all the evidence before it. The IRP will then either uphold or reverse the CCG's decision.



# How to challenge the CHC eligibility decision made by the CCG in 4 steps

4. You may take your case to the Parliamentary and Health Service Ombudsman, if you are dissatisfied with the outcome of the review.

The Parliamentary and Health Service Ombudsman is an independent body that has the power to investigate complaints against a range of public bodies, including the NHS. Once you have written to the Ombudsman, they will acknowledge receipt of your complaint within 2 working days. The investigation by the Ombudsman focuses on whether the correct processes and procedures have been followed. The Ombudsman can make a range of decisions. They may decide not to investigate your complaint further or may decide to grant CHC.

At each stage of the appeal process, you should carefully consider the merits of your case and take into account the time taken to pursue your appeal.

# Alternative Sources of Funding: FNC and local council funding

## a) NHS-funded nursing care (FNC)

If the person you are caring for does not qualify for CHC but is nonetheless assessed as requiring nursing care, there is an alternative NHS funding option, namely FNC. FNC is a standard rate contribution made by the NHS towards the cost of providing registered nursing care in a nursing home. You or your local council will have to cover the rest of the nursing home fees.

Eligibility for CHC should in all cases be first considered before a decision is reached about the need for FNC. Consequently, most people will not need to have a separate assessment for FNC if they have already had a full assessment for CHC. If, however, an assessment is needed for FNC, the CCG can arrange it

# Alternative Sources of Funding: FNC and local council funding

## b) Local council funding

Additionally or alternatively, your local council may be able to provide funding, depending on the financial situation of the person being cared for.

For further details about how to access social care and local council funding, please refer to the information compiled by the Alzheimer's Society at <https://www.alzheimers.org.uk/get-support/legal-financial/assessment-care-support-england#content-start>

# Carers

A carer is defined by the Care Act 2014 as an unpaid “adult who provides or intends to provide care for another adult” who needs care. The care does not have to be substantial or regular. Additionally, it is not limited to physical care, it can also be emotional.

According to the Statutory Guidelines, the definition of ‘an adult needing care’ arises from ‘physical, mental, sensory, learning or cognitive disabilities or illness, substance misuse or brain injury’ (6.104)

As a carer, your wellbeing will be considered alongside the wellbeing of the person who you care for. You may receive support to meet your needs, if there are eligible needs.

In order to qualify for this support, you will need to undertake a free care assessment.

# Care Assessment

A Care Assessment is free and optional.

Your local authority can offer you one, if it appears to them that you need one. But you can choose to accept or reject it. In case they do not offer you a care assessment, you can request it.

The assessment consists of a conversation between you and someone from your local authority, so they can assess your eligible needs.

The assessment can help you identify what your needs are and give you information as to what services or funding are available to support you. Depending on the type of help or support you need, the outcome of the assessment may help with your relationships, employment and recreational activities.

# How to prepare for the Care Assessment

The assessment can be done by phone, in person or online.

You can request for the questions to be provided beforehand.

In preparation, you should compile as much evidence of your needs as possible.

You can also request they indicate a reasonable timescale for how long the process will take.



# How-to prepare for the Care Assessment

## Aim of the assessment:

- Which needs are eligible for support
- How sustainable your caring role is
- The outcomes you want to achieve and the impact of your caring role on those outcomes
- The development of a support plan/plan of action to meet your needs

# How-to prepare for the Care Assessment (I)

## Your Carer needs are eligible if:

a) Your physical or mental health is deteriorating or is at risk of deteriorating OR you are unable to achieve any one of the following outcomes:

- Carrying out any caring responsibilities you have for a child;
- Providing care to other persons for whom you provide care;
- Maintaining a habitable home environment in your home;
- Managing and maintaining nutrition;
- Developing and maintaining family or other personal relationships;
- Engaging in work, training, education or volunteering;
- Making use of necessary facilities or services in the local community, including recreational facilities or services;
- Engaging in recreational activities.

AND (next page)



# How-to prepare for the Care Assessment (II)

b) As a consequence, there is or it is likely to be a significant impact on your wellbeing.

Well-being includes:

- Personal dignity (including treatment of the individual with respect)
- Physical and mental health and emotional wellbeing
- Protection from abuse and neglect
- Control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- Participation in work, education, training or recreation
- Social and economic wellbeing
- Domestic, family and personal relationships
- Sustainability of living accommodation
- The individual's contribution to society

# What help is available to me as a 'carer'?

Through the care assessment, carers are entitled to the creation of a support plan. A support plan will assist in the management of your mental, physical and emotional wellbeing while you care for another person.

The support plan will offer information on various topics, including:

- Getting someone to take over caring so you can take a break, otherwise known as respite
- Access to programs which help you relax
- Covering taxi fares if you do not drive
- Training on how to provide physical care
- Advice about benefits for carers

Support plans can result in three forms of monetary support. They are:

- A Personal Budget
- The Carer's Allowance
- The Carer's Credit



## How to apply for a Carer's Allowance

# What are the requirements for a Carer's Allowance? (I)

The person you care for must already get one of the following benefits:

- **Personal Independence Payment - daily living component**
- **Disability Living Allowance - the middle or highest care rate**
- **Attendance Allowance Constant Attendance Allowance at or above the normal maximum rate with an Industrial Injuries Disablement Benefit**
- **Constant Attendance Allowance at the basic (full day) rate with a War Disablement Pension**
- **Armed Forces Independence Payment**

# What are the requirements for a Carer's Allowance? (II)

The carer must:

- Care for someone more than 35 hrs a week
  - This can include cooking and washing, taking the person to a doctor's appointment, or helping with household tasks such as shopping
- Be over the age of 16
- Have lived in England, Scotland or Wales for at least 2 of the last 3 years (this does not apply if you have refugee status or humanitarian protection status)
- Not be in full time education
- If you are in part time education, that it is not over 21 hours per week
- Not be subject to immigration control
- Your earnings must be less than £128 per week

## How this affects the carer: (I)

In some cases this means you may get extra support, such as a reduction in your Council Tax for being a carer.

The Carer's Allowance does not count towards the benefits cap for the carer applying.

In other cases, this will result in a limit of the amount of benefits funding you will receive as you are not allowed to get certain types of benefits along with your Carer's Allowance.

## How this affects the carer: (II)

These benefits include:

- State Pension
- Incapacity Benefit
- Severe Disablement Allowance
- Unemployability Supplement – paid with Industrial Injuries Disablement Benefit or War Pension
- Widow's Pension or Bereavement Allowance
- Widowed Mother's Allowance or Widowed Parent's Allowance
- War Widow's or Widower's Pension
- Maternity Allowance
- Industrial Death Benefit
- Contribution-based Jobseeker's Allowance
- Contribution-based Employment and Support Allowance

## How this affects the supported person:

If you claim the Carer's Allowance, the person you care for will stop receiving:

- Any severe disability premium paid with their benefits
- Any extra amount for severe disability paid with their pension credit, if they receive one
- They may also stop receiving reduced Council Tax





## How to apply:

The Carer's Allowance is applied for online at the following website: <https://www.gov.uk/carers-allowance/how-to-claim>

Click the green “apply now” button and follow the guided steps.

If you cannot apply online, you can also apply by post. The form is located here: <https://www.gov.uk/government/publications/carers-allowance-claim-form>

It is important to note that applying for Carer's Allowance may affect the benefits of the person you are supporting, or any benefits which you yourself receive.



## How to apply for Carer's Credit

# What are the requirements for Carer's Credit? (I)

The person you care for must get one of the following benefits:

- Disability Living Allowance care component at the middle or highest rate
- Attendance Allowance
- Constant Attendance Allowance Personal Independence Payment - daily living component, at the standard or enhanced rate
- Armed Forces Independence Payment

If the person you care for does not get one of these benefits, you may still be eligible for the carer's credit. A health or social care professional can sign the "Care Certificate" part of the application for you.

# What are the requirements for Carer's Credit? (II)

The carer must:

- Be aged 16 or over
- Under state pension age
- And looking after a person for more than 20 hours a week

More information can be found at <https://www.gov.uk/carers-credit>

## How to apply for Carer's Credit?

The Carer's Credit is applied for via a mailed in form.

The form is located at:

<https://www.gov.uk/government/publications/carers-credit-application-form>

It should be mailed to:

Carer's Allowance Unit

Mail Handling Site A

Wolverhampton

WV98 2AB

# Planning Ahead

## Creating a Lasting Power of Attorney

When the person that you're caring for is believed to have dementia, or has been diagnosed with the condition, it is important to plan ahead for the future.

One way of doing this is by creating a lasting power of attorney (LPA). An LPA can be created by the person with dementia in order to give you legal permission to make decisions on their behalf.



## Step 1: Is the person you're caring for able to create an LPA?

In order to be able to create an LPA in the first place, the person you're caring for must be over the age of 18 and must have capacity to create the LPA. The fact that the person you're caring for has dementia does not necessarily prevent them from having capacity to create an LPA.

They will only lack capacity if, for any reason including their dementia, they are unable to understand, retain and weigh up the relevant information about the LPA in order to come to a decision on whether to go ahead with it.

They must be able to decide for themselves that they want to create an LPA. If they do lack capacity, they will be unable to create an LPA. For further guidance on lack of capacity, please see the information below on Deputyship.

## Step 2: Choose what type of LPA the person you're caring for wants to create

There are two types of LPA which can be created: financial LPAs and health and care LPAs.

Financial LPAs will give you the power to make decisions on behalf of the person you're caring for about things like tax, bills, bank accounts, property, investments, pensions and benefits.

A health and care LPA, on the other hand, will give you the ability to make decisions about the health and care of the person you're caring for. These decisions may involve the person's daily routine, their medical care and where they live.

You can create one or both LPAs. Please note, however, that whilst financial LPAs can come into effect whilst the person making the LPA still has capacity to make their own decisions if that is stated in the LPA, health and care LPAs can only be used when they lack capacity to make health and care decisions themselves.



## Step 3: Get the LPA forms

In order to create a valid LPA, you should use the forms available on the government's website at this web address:

<https://www.gov.uk/government/publications/make-a-lasting-power-of-attorney>

To create a financial LPA you should use the LP1F form. To create a health and care LPA you should use the LP1H form.

You can either fill in the forms online or you can print them out and fill them in on paper.

## Step 4: Choose who will be appointed as attorneys and note this on the forms

Next, the person you are caring for must decide who they want to appoint as the attorneys who will be able to make decisions on their behalf - this, presumably, will include yourself.

They can also appoint as many other attorneys as they would like. Any appointed attorney must, however, be over the age of 18 and have capacity to take on the role.

Additionally, for financial LPAs, the attorneys must not be bankrupt. If multiple attorneys are appointed, the person creating the LPA should also note whether the attorneys should make decisions 'jointly' or 'jointly and severally'

i.e. whether the attorneys must all agree in order to be able to make a decision or whether one of the attorneys can make a decision alone.

It is also possible to appoint replacement attorneys who will take over if one of the appointed attorneys stops being able to perform the role.

## **Step 5: Decide whether to include preferences or instructions for the attorneys and note this on the forms (I)**

There is an opportunity, when filling out the LPA forms, for the person you are caring for to establish some preferences and instructions for their attorneys.

Preferences are things that they wish their attorneys to take into account when making decisions on their behalf.

- An example of a preference would be “I would like to spend time outdoors at least once a day”.

Instructions, on the other hand, are things that the attorneys are legally bound to do when making decisions on behalf of the person creating the LPA.

- An example of an instruction would be “My attorneys must not sell my home unless, in my doctor’s opinion, I can no longer live independently”

## Step 5: Decide whether to include preferences or instructions for the attorneys and note this on the forms (II)

Whilst preferences and instructions can be a good way of ensuring that a person with dementia's wishes are followed when they can no longer make their own decisions, they can also create difficulties for attorneys in the future.

It is a good idea to seek legal advice from a solicitor if the person you're caring for wishes to include instructions in their LPA.

## Step 6: Sign the LPA forms

In order to be valid, the LPA forms must have been signed by the person creating the LPA, the attorney(s), a witness and a certificate provider.

The witness can be anybody over the age of 18 who has capacity except for the person creating the LPA.

The certificate provider's role is to confirm that the person creating the LPA has the capacity to do so, understands what the LPA means for them and has not been pressured or unduly influenced into creating the LPA.

The certificate provider must, again, be over the age of 18 and have capacity to act as a certificate provider.

Additionally, they must either have relevant professional skills e.g. a doctor or a lawyer, or they must be someone who has known the person creating the LPA for at least two years e.g. a friend or colleague.

## Step 7: Is the person creating the LPA exempt from paying the registration fee? (I)

Before sending off the forms, it is a good idea to determine whether or not the person you're caring for is likely to be exempt from paying the registration fee for the LPA, or whether they can get a discount.

Typically, it costs £82 to create an LPA. If you want to create both a financial LPA and a health and care LPA it will therefore cost £164.

The person you're caring for may not have to pay anything to create the LPA if they receive certain means-tested benefits.

## Step 7: Is the person creating the LPA exempt from paying the registration fee? (II)

These benefits are:

- Income Support
- Income-based Employment and Support Allowance
- Income-based Jobseeker's Allowance
- Guarantee Credit element of State Pension Credit
- Housing Benefit
- Council Tax Reduction/Support – also known by other names (not the 25% single person discount or the Class U exemption)
- Local Housing Allowance
- A combination of Working Tax Credit and at least one of:
  - Child Tax Credit;
  - Disability Element of Working Tax Credit
  - Severe Disability Element of Working Tax Credit

## Step 7: Is the person creating the LPA exempt from paying the registration fee? (III)

If they do not receive any of these benefits, they may be able to get a 50% discount on the registration fee if their annual income is less than £12,000.

If you believe that they may be eligible for either the exemption or the discount, you should tick the appropriate box on the LPA forms, under the “Application Fee” section. You should also gather evidence which proves that the person you’re caring for is eligible for the exemption or discount which can be sent with the LPA forms in the next step.



## Step 8: Register the LPA

Finally, the LPA must be registered with the Office of the Public Guardian. This is done by sending the forms to the following address:

Office of the Public Guardian,

PO Box 16185,

Birmingham,

B2 2WH

Registering the LPA can take up to 15 weeks as the Office of the Public Guardian processes the LPA application form. The LPA is not effective and cannot be used until it has been registered successfully.

# After the LPA has been created (I)

## Notify people

Once the LPA has been registered successfully, you should notify the relevant people that you will be able to make decisions on behalf of the person you're caring for when they are unable to make decisions for themselves.

These people likely include their GP or healthcare workers if it is a health and care LPA, and their bank if it is a financial LPA.

## After the LPA has been created (II)

### Your Duties as an Attorney

Attorneys have a number of duties and responsibilities. They must always act in the best interests of the person who created the LPA, and they have a duty of care towards them. They must assume that the person who created the LPA does have capacity to make decisions unless it's established that they don't, and all practicable steps must be taken to help the person who created the LPA to make decisions for themselves. Attorneys must not delegate their responsibilities unless it's stated in the LPA that they can, and they must keep the person who created the LPA's information confidential.

# Advance Decisions

An advance decision allows a person to refuse a specific type of medical treatment in the future in particular circumstances.



# Advance decisions (I)

An advance decision allows individuals to determine to refuse specified medical treatment in the future when they may lack capacity to refuse or consent to that medical treatment.

The advance decision must be valid and applicable to the circumstances the individual finds themselves in which will give the decision the same effect as one made by a person with capacity.

It will also require healthcare professionals to follow the advance decision. A healthcare professional can be prosecuted if they do not follow the advance decision but it also means they will not be held liable if they withhold treatment because there is a reasonable belief that the advance decision applies.

# Advance decisions (II)

In order to be valid the advance decision must be:

- in writing
- signed by the person with dementia or, if the person with dementia is unable to sign, by someone else on behalf of the person with dementia in their presence and at their direction
- the person with dementia's signature must be done in the presence of a witness, who must also sign the document in the person with dementia's presence
- the document must also be verified by a statement made by the person with dementia which expressly states that the advance decision applies to the specific treatment even if their life is at risk
- this statement must also be signed by the person with dementia in the presence of a witness, who must also sign the statement.
- made by someone over 18
- made by someone with capacity to make that decision at the time of making the decision

## Advance decisions (III)

It is also wise to consult a professional in this expert who should ensure that the person has considered any future circumstances and whether the refusal of medical treatment would always be applicable.

They should also discuss whether the person with dementia's family members and carers have been made aware of the terms of the advance decision.



# Advance decisions (IV)

It must be stressed that a written decision is always preferable but if an oral decision is the only one available, then it must be stated that the decision will apply if the person with dementia does not have capacity in the future to make decisions on treatment. It must also be as clear as possible with specific exact details of the treatments, the decision and the circumstances. There must also be some record of those present when the decision was made and their relationship to the person making the decision.

The written decision should include the above details and should also include personal details such as the person with dementia's name, address and date of birth and the date of the document.



# Advance decisions (V)

Regarding life-sustaining treatment, requirements that should be complied with include the decision being written and signed either by or for the person with dementia and the consultation of a healthcare professional who will indicate the various consequences that will be created by the decision.

Any advance decision must be applicable to the treatment being administered in the circumstances. It would not be classed as applicable if the person with dementia has the capacity to consent or refuse the treatment, if the treatment is not the treatment specified in the advance decision and if the circumstances are not what was anticipated when the advance decision was made.

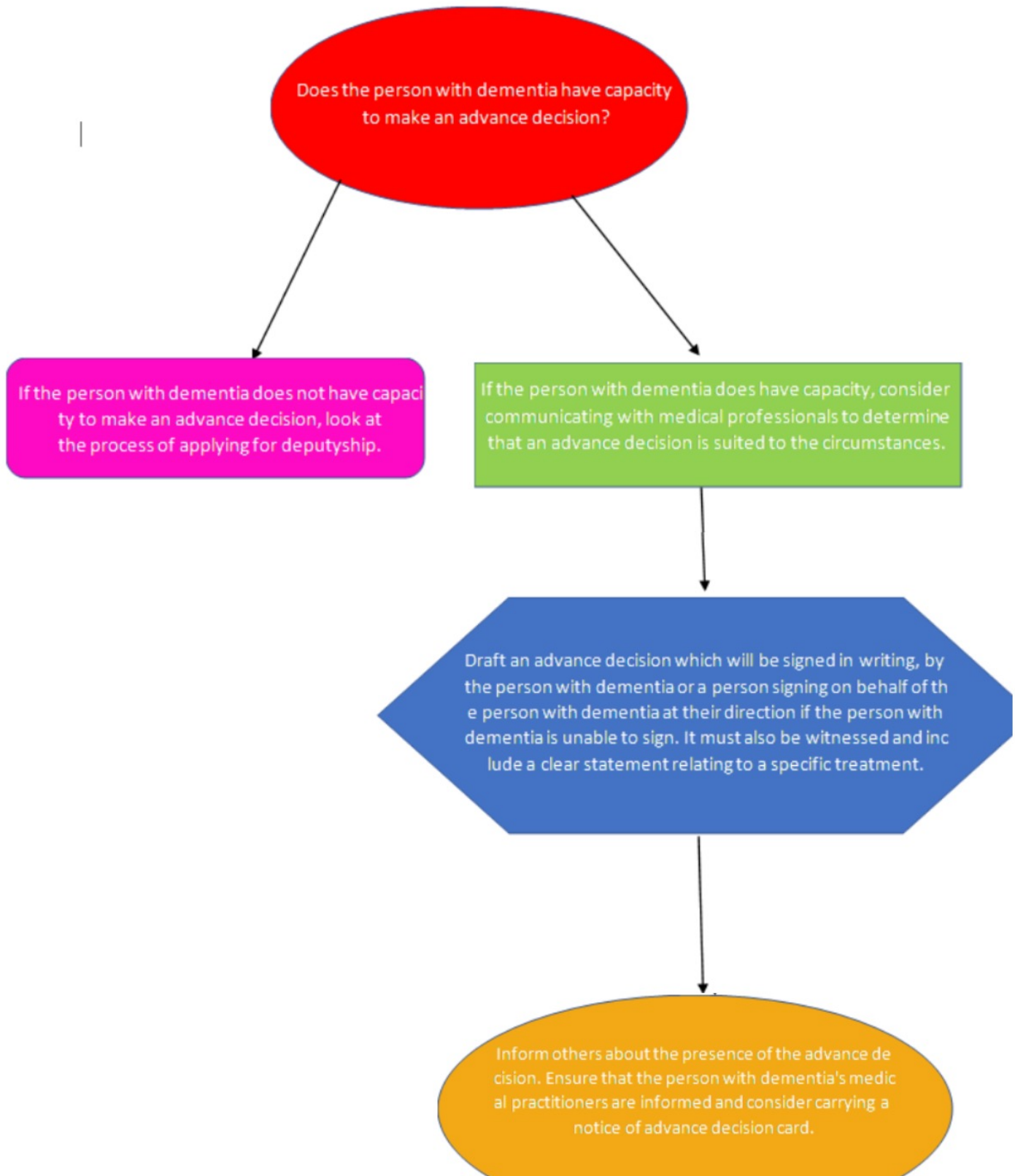
# Advance decisions (VI)

The person with dementia should review their decision regularly to ensure that it still remains both valid and applicable.

This could include:

- Signing and dating their decision after reviewing it and sending a copy of the reviewed decision to everybody with the original copy
- Avoiding including a review date in the decision as it will create uncertainty as to whether the decision had a time limit

# Flowchart of Advance Decisions



# Advantages of Advance Decisions

It allows the person with dementia to be certain that their wishes will be complied with even if they lose capacity and that their feelings will be respected even if there is any disagreement amongst those with an interest in their welfare.

It is a record of the person with dementia's wishes that can be used even if not valid to determine the best course of action for their care.

It becomes effective immediately which is helpful if it is assumed that incapacity will occur soon.

# Disadvantages of Advance Decisions (I)

They do not need to be formally registered which means the person with dementia must ensure that family members, anyone involved in their care and anyone who may treat them in an emergency are aware of the advance decision.

Circumstances may occur that would have led the person with dementia to have wanted to refuse treatment if they had been aware of the circumstances at the time of making the advance decision but they would be unable to apply the advance decision if the circumstances were not those specified in the advance decision.

# Disadvantages of Advance Decisions (II)

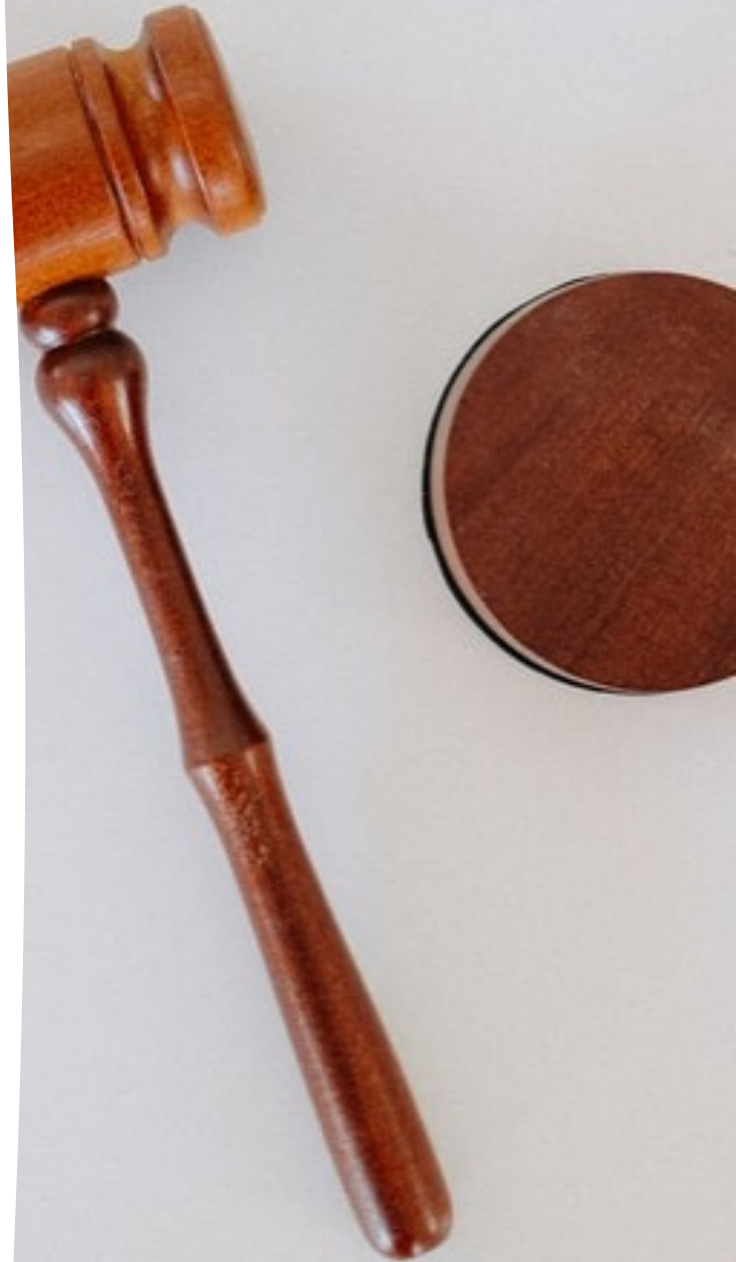
The person with dementia's actions can invalidate their advance decision if it can be seen that their later behaviour is inconsistent with the advance decision.

The lack of formality can lead to oral advance decisions leading to misinterpretation and confusion.

# Deputyship

Losing capacity occurs when a person struggles to decide for themselves. They have a mental issue that affects their everyday decisions. They may have Alzheimer's, Dementia or a brain injury

The Court of Protection gives powers to someone to make certain decisions on behalf of the person who lost capacity. If you are acting on behalf of somebody else, you are called a deputy.



# How to apply to become a deputy (I)

Complete the following documents:

## 1. Main application form (COP1)

<https://www.gov.uk/government/publications/apply-to-make-decisions-on-someones-behalf-form-cop1>

## 2. Annex A: supporting information for property and affairs (COP1A)

<https://www.gov.uk/government/publications/apply-to-make-decisions-on-someones-behalf-property-and-finance-form-cop1a>

## 3. Annex B: supporting information for personal welfare applications (COP1B) – for personal welfare deputyship only

<https://www.gov.uk/government/publications/apply-to-make-decisions-on-someones-behalf-personal-welfare-form-cop1b>



# How to apply to become a deputy (II)

## 4. Assessment of capacity (COP3)

<https://www.gov.uk/government/publications/make-a-report-on-someones-capacity-to-make-decisions-form-cop3>

## 5. Deputy's declaration (COP4)

<https://www.gov.uk/government/publications/apply-to-become-someones-deputy-make-a-declaration-form-cop4>

The COP4 outlines your circumstances and includes details of responsibilities and duties the deputy must carry out. The court needs assurance that the deputy can carry this out.

# How to apply to become a deputy (III)

Send the forms, including 2 copies of the application form (COP1), to the Court of Protection with a cheque for the application fee to:

Court of Protection

PO Box 70185

First Avenue House

42-49 High Holborn

London

WC1A 9JA

You must name at least 3 people in your application who know the person you are applying to be deputy for.

# How to apply to become a deputy (IV)

In some cases, you may be asked to complete:

- Permission of the court to apply (COP2) – this is usual for personal welfare but not property and affairs
- A witness statement (COP24) – this may be required if you are unable to submit an assessment of capacity form (COP3). The COP24 can be used to explain why you are unable to do so and why you think the person you are applying to be a deputy for lacks capacity.

These forms can be obtained from the court of protection and solicitors can help with this.

# How to apply to become a deputy (V)

You must tell the person you are applying to be deputy for:

- Who's applying to be their deputy
- That their ability to make decisions is being questioned
- What having a deputy would mean for them
- Where to get advice if they want to discuss the application

# How to apply to become a deputy (VI)

You must also give them:

- A completed proceedings notification form (COP14)

→ <https://www.gov.uk/government/publications/court-of-protection-proceedings-notification-form-cop14>

→ Guidance for this:

<https://www.gov.uk/government/publications/court-of-protection-proceedings-notification-form-cop14>

- An acknowledgment form (COP5)

→ <https://www.gov.uk/government/publications/apply-to-be-part-of-court-of-protection-proceedings-form-cop5>

They need to give their opinion on the application and provide evidence.

- Any other documents related to your application.

# How to apply to become a deputy (VII)

The person who you are applying to be a deputy for must fill in this form:

<https://www.gov.uk/government/publications/form-cop20a-certificate-of-notification-non-notification-of-the-person-to-whom-the-proceedings-relate>

The other people named in the document must fill in this form:

<https://www.gov.uk/government/publications/form-cop20b-certificate-of-service-non-service-notification-non-notification>

# Signposting

Name of service:	Type of service:	Contact details
Age UK	Providing companionship, advice & support for older people	Tel: 0800 678 1602 (advice line open 8am–7pm every day) Email: <a href="mailto:contact@ageuk.org.uk">contact@ageuk.org.uk</a> Website: <a href="http://www.ageuk.org.uk">www.ageuk.org.uk</a>
Alzheimer's Society	Help with care	Support Line Tel: 0333 150 3456 Tel: 1800 1 0300 222 1122 (for those with speech or hearing difficulties and have a textphone or an adapted computer and use Text Relay)  Lines open: Monday – Wednesday 9am – 8pm Thursday & Friday 9am – 5pm Saturday and Sunday 10am – 4pm  General Enquiries Tel: 0330 333 0804 8am – 10pm lines open every day (except Christmas day) Online: <a href="https://www.alzheimers.org.uk/form/contact-us-general-enquiries">https://www.alzheimers.org.uk/form/contact-us-general-enquiries</a>  Online support messaging: <a href="https://dementiaconnect.alzheimers.org.uk/?_ga=2.128451214.388044294.1607611655-1960316724.1584975499">https://dementiaconnect.alzheimers.org.uk/?_ga=2.128451214.388044294.1607611655-1960316724.1584975499</a>  Website: <a href="https://www.alzheimers.org.uk/get-support/help-dementia-care/looking-after-yourself#content-start">https://www.alzheimers.org.uk/get-support/help-dementia-care/looking-after-yourself#content-start</a>
Alzheimer's Society (cont'd)		Financial care and support website: <a href="https://www.alzheimers.org.uk/get-support/legal-financial/who-pays-care">https://www.alzheimers.org.uk/get-support/legal-financial/who-pays-care</a>  Replacement (respite) care website: <a href="https://www.alzheimers.org.uk/get-support/help-dementia-care/replacement-care-more-resources#content-start">https://www.alzheimers.org.uk/get-support/help-dementia-care/replacement-care-more-resources#content-start</a>  Practical guide for caring for a person with dementia: <a href="https://www.alzheimers.org.uk/get-support/publications-factsheets/caring-person-dementia-practical-guide">https://www.alzheimers.org.uk/get-support/publications-factsheets/caring-person-dementia-practical-guide</a>
Carers Trust	Working to improve support, services & raising awareness of unpaid carers in the UK	Tel: 0300 772 9600 Email: <a href="mailto:info@carers.org">info@carers.org</a> Website: <a href="http://www.carers.org">www.carers.org</a>
Carers UK	Making life better for carers	Tel: 0808 808 7777 (Lines open Monday to Friday, 9am – 6pm)  Online form: <a href="https://www.carersuk.org/about-us/contact-us">https://www.carersuk.org/about-us/contact-us</a>  Website: <a href="http://www.carersuk.org">www.carersuk.org</a>
Cruse Bereavement Care	Helping with bereavement	Tel: 0808 808 1677 (Lines open 9:30am–5pm Monday, 9:30am–8pm Tuesday–Thursday & weekends 10am–2pm)  Online chat: <a href="https://www.cruse.org.uk/get-help/crusechat/">https://www.cruse.org.uk/get-help/crusechat/</a>  Website: <a href="http://www.cruse.org.uk">www.cruse.org.uk</a>
Culture Dementia	Supporting carers and people	Tel: 0800 014 8682 (24 hour service)

# Signposting

<b>UK</b>	living with dementia amongst the African/ Caribbean community	Online advice: <a href="https://www.culturedementiauk.org/contact">https://www.culturedementiauk.org/contact</a> Website: <a href="https://www.culturedementiauk.org/">https://www.culturedementiauk.org/</a>
<b>Dementia UK</b>	Providing specialist dementia support including their Admiral Nurse service	Tel: 0800 888 6678 Email: <a href="mailto:helpline@dementiauk.org">helpline@dementiauk.org</a> Website: <a href="https://www.dementiauk.org/">https://www.dementiauk.org/</a>
<b>Dementia Engagement and Empowerment Project (DEEP)</b>	Group support for people with dementia	Tel: Rachel Niblock (UK Coordinator) 07720 538851 Email: <a href="mailto:niblock@myid.org.uk">niblock@myid.org.uk</a> Website: <a href="https://www.dementivoices.org.uk/">https://www.dementivoices.org.uk/</a>
<b>Dementia Shop</b>	Online shop & advice platform	Tel: 0207 377 2885 Email: <a href="mailto:dementiashop@stir.ac.uk">dementiashop@stir.ac.uk</a> Website: <a href="http://www.dementiashop.co.uk">http://www.dementiashop.co.uk</a>
<b>Independent Age</b>	Information & advice; support & campaigning	Tel: 0800 319 6789 & 0207 605 4200 Email: <a href="mailto:advice@independentage.org">advice@independentage.org</a> Website: <a href="https://www.independentage.org/">https://www.independentage.org/</a>
<b>Making Space</b>	Supporting people to live well with dementia	Tel: 01925 571 680 Online form: <a href="https://makingspace.co.uk/contact">https://makingspace.co.uk/contact</a>
		Website: <a href="https://makingspace.co.uk/services/dementia">https://makingspace.co.uk/services/dementia</a>
<b>NHS</b>	Online advice page	Website: <a href="https://www.nhs.uk/conditions/dementia/carers/">https://www.nhs.uk/conditions/dementia/carers/</a>
<b>Samaritans</b>	Emotional help for people having a difficult time & struggling to cope	Tel: 116 123 (free any time) Email: <a href="mailto:jo@samaritans.org">jo@samaritans.org</a> Website: <a href="https://www.samaritans.org/">https://www.samaritans.org/</a>
<b>Tide – together in dementia everyday</b>	Building a better future for carers of people with dementia	Tel: 0151 237 2669 Email: <a href="mailto:carers@tide.uk.net">carers@tide.uk.net</a> Website: <a href="https://www.tide.uk.net/">https://www.tide.uk.net/</a>
<b>University of Manchester Dementia Law Centre</b>	Legal written advice from supervised university students	Tel: 0161 275 7976 Email: <a href="mailto:free.legal@manchester.ac.uk">free.legal@manchester.ac.uk</a> Online form: <a href="https://www.socialsciences.manchester.ac.uk/legal-advice-centre/services/request-an-appointment/">https://www.socialsciences.manchester.ac.uk/legal-advice-centre/services/request-an-appointment/</a> Website: <a href="https://www.socialsciences.manchester.ac.uk/legal-advice-centre/">https://www.socialsciences.manchester.ac.uk/legal-advice-centre/</a>