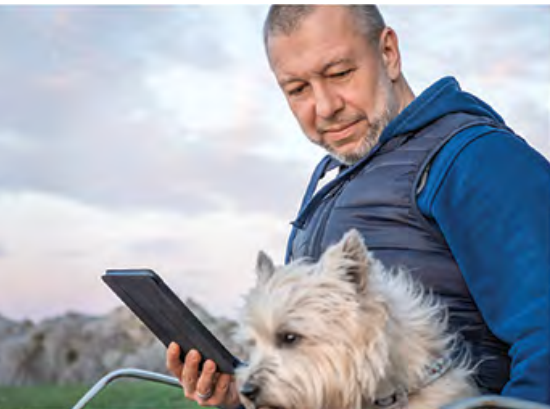


# Forward with dementia

A guide to living with dementia



## The challenge and strategies tool

For social prescribers supporting GP surgeries and local authorities or anyone new to dementia.

## The nine sections of guidance

Pre-contact and referral

First contact

Building trust and rapport

Identifying needs

Identifying and  
signposting to resources

Engaging people living  
with dementia

Your emotional reactions

Discharge and the  
continuity of care

Professional development  
and training

**In this guide you will find nine sections covering challenges you may be faced with as a social prescriber and strategies you may want to try to handle them.**

This tool has been built to support the care of those living with dementia by social prescribers.

Explore this resource in any way or work through the sections in the order representing the consultation journey for people living with dementia.

All the advice is based on input from our co-creative dementia team comprising fellow healthcare professionals as well as care partners and people living with dementia.

**Dementia.  
Feel better  
prepared**

Other suggestions, insights and plans are available free, on any device at [forwardwithdementia.org](https://forwardwithdementia.org)  
A practical guide for living with dementia

## Using the guide

Across this tool you will find organised lists of challenges and strategies.

You will also find case studies that put the advice into context.

You can find these by looking for:



This PDF version is great to use when you are offline or out of mobile or wifi connection but there is a online version too at:

[forwardwithdementia.org/en/social-prescribing-and-dementia/](https://forwardwithdementia.org/en/social-prescribing-and-dementia/)

This tool aims to be a guide that can help you with dementia conversations and personal care planning if you have not had too much experience working with people living with dementia.

The strategies we list have been recommended by those working as social prescribers.

At the time of publishing social prescribing services are by no means consistent across the UK but we have included advice from social prescribing practitioners and dementia research teams to help as many people as possible.

If you have any suggestions or additions for this tool please do get in touch.

To contact the UK research team, please email:

[forwardwithdementia@ucl.ac.uk](mailto:forwardwithdementia@ucl.ac.uk)

**Dementia.  
Losing the  
stigma.**

Tailored suggestions, insights and plans are available free, on any device for anyone living with dementia at [forwardwithdementia.org/en/living-with-dementia](https://forwardwithdementia.org/en/living-with-dementia)

# 1 • Pre-contact and referral

## You lack confidence or experience in dementia

Strategies you may want to try

**Consider expertise** within your team to get guidance. In some cases, social prescribers have found it helpful to pass the referral to a more experienced colleagues in their team.

### **Be pro-active, not reactive.**

Do some preliminary research (online and in person), finding the charities or the statutory services that your patient can be signposted to. In most instances your locality will have a web-based directory where you can find what is going on. Sometimes, GPs, PCNs, or charities have directories that they have collated, or the information might be available if you speak with others in the team.

*Also See the section on professional development.*

## You are passed on a referral with little to no information on the patient's situation

Strategies you may want to try

### **If you work in PCNs, get access to the GP records.**

You can see what was said during the consultation and what prompted the referral. However, check with the patient that the need identified in the original referral is still unaddressed or if anything has changed, as they might need something else.

### **If you work in a charity,**

you will be relying on information relayed to you by the patient, which may be inaccurate. Consider involving caregivers/families in the conversations



## Your referral is placed in a long waiting list, due to the amount of referrals you receive

### Strategies you may want to try

Prioritise referrals in a matter of urgency. Urgency could be risk of homelessness, no food, no gas and electric. High priority could be struggling financially (because of lack of attendance in place). Moderate could be an interest in social groups or activities.

## You are unsure who you will speak to when contacting the patient

### Strategies you may want to try

You may want to explore whether legal arrangements are in place, such as lasting power of attorney or who gave consent in the referral process.

This will clarify who you will be having

discussions with and most importantly who will have a final say in any course of action.

## You are unsure about what is going on in the community to support your patient

### Strategies you may want to try

Social prescribers often report feeling “Jack of all trades, masters of none”. You may want to consider signing up to newsletter and mailing lists of different/relevant organisations such as the National Academy for Social Prescribing: [socialprescribingacademy.org.uk/](https://socialprescribingacademy.org.uk/). Getting in touch at intervals with organisations, to see if there is anything new that you have missed, is also helpful



## You want to make sure that the patient knows you are going to contact/ring them

### Strategies you may want to try

You may want to consider posting a letter via regular mail. Not only are older generations more familiar with regular mail than e-mail, but also it is best for people living with dementia to have a physical/readily available reminder about the appointment.



## Danielle's story

### Pre-contact groundwork and preparation

Danielle is a social prescribing link worker in a PCN with previous experience of social prescribing in the voluntary sector. They share their experience of routine pre-contact stages and some insight and tips on how to prepare to support a client with dementia who has been referred to them.

Danielle believes that there is some due diligence groundwork that a social prescriber should undertake to be better prepared and make the most of their (limited) time with their client with dementia. When a referral is received, Danielle often feels that the information provided lacks details:

*"In the referral, it tells me who's made the referral, their contact details and usually a little bit about the situation. It is very dry, doesn't tell me where the person is accepting of it, whether he wants to talk, whether they are going to come out, what their prognosis is, if there's anything else".*





Therefore, Danielle finds that some further digging is required to obtain clients' information.

Having experience of working within PCNs and charities, Danielle recognises that having access to clients' records within PCNs is advantageous at the point of referral, as it allows the social prescriber to gather reliable and accurate background information on clients:

*"PCN versus charity referral, the most important difference is that through a PCN I can see people's medical records. So, before I meet them, I have a much clearer idea of what exactly their diagnosis is, and I know whether they've got consent for relatives to speak for them, whereas working in the voluntary organisation you don't have access to any of that and you're very reliant on what people tell you, which is not always the whole truth".*

Before taking on a client, Danielle finds it very helpful to discuss with their own team who is the most appropriate person to support that client, based on the background information available:

*"We consider expertise within your team. The way it happens is the GP will send the referral through. Our team get together, and we'll look at the referrals and*

*we see who's better suited for that client based on our different background and expertise".*

Because of the very large number of referrals, Danielle's team have also implemented a traffic light system based on matter of urgency:

*"When we get the referral, they get added onto our waiting list, which is quite long just due to the number of referrals that we receive. We prioritise referrals in a matter of urgency. So, say if something comes up which is quite urgent, we will try to prioritise that and contact them within a few days to obviously address the issue as quick as we can. Say urgency would be homeless, no food, no gas and electric. Then, we have high priority which it may be struggling financially and sometimes we get referrals for people with dementia, and they haven't got attendance. So, we tend to put them on high priority just because how long the process takes to claim. And then we have moderate, which would be people that are maybe just interested in social groups or activities".*

Once the social prescriber is ready to open the referral based on matter of urgency and expertise





within the team, they would undertake some preliminary research. Danielle finds this helpful to get a sense of what potential resources are available in the community:

*"That normally starts online, to find the charities that are involved or the statutory services that might be able to support with this case".*

It is also good practice with clients with dementia to start communication in paper format:

*"We would send a letter first, so they've got a letter to see who we are, why we're ringing and when we intend to ring. If we have their permission to contact a family member, then we would be contacting the family member as well. But I think if they've got something in writing, they can pop that in the calendar. If not, we would hope that a family member might pick that letter".*

When making first contact, it may come up that the caregiver or family member wishes to be involved in the support of the person they care for. Or it may become evident that the client with dementia would struggle to engage if unsupported. In that case, Danielle suggests considering submitting a request

to change the name on the from the client with dementia to the caregiver. But this needs careful consideration:

*"I have been known to go back and say to the GP - would it be easier if you put the referral in the carer's name? Because you're then kind of scooping both up with one go. It's to make things much easier, dealing with the couple, if that's appropriate. It's not always appropriate. If there's no communication issues, you go straight to the patient with the dementia. Maybe it's an early diagnosis and they're functioning very well".*

Finally, when making first contact, it is important to remember that clinical notes may reflect GPs' views of clients' needs, and that there may be discrepancies with clients' views.

Needs may also change between referral and first contact. Therefore, Danielle suggests, double checking with the clients themselves reason for referral as soon as possible:

***"Even when I read the notes on the GP, I like to let the patient lead the conversation because what they said during that consultation with the doctor might change. They might need something else".***





## 2 • First contact

### You realise that the patient has communication issues

(e.g., the ability to relay accurate information)

#### Strategies you may want to try

**Consider going back to the GP** and asking them to make a referral for the caregiver, so you can support the couple. Remember that dementia is a systemic issue that does not affect the person only, but also (and sometimes even more) the caregiver/family. Whilst operating in a person-centred approach is key to social prescribing, it is equally important not to overlook the carer and how their health and wellbeing also affects the person living with dementia.

**Suggest a face-to-face appointment**, either at the surgery (saves time and resources), at the patient's home (if the person cannot travel) or at a community place. Especially in cases of mid to late-stage dementia, it is advisable to have the carer/family present.

**Be aware that there may language barriers** with non-native English speakers.

The patient may have reached a point in their life where they spoke great English, but because of the dementia they are now reversing back to their native language. You may want to consider using a translator (if available), although some find it more effective to involve a family member because they know the person better.



## **You realise that the patient may have issues around capacity**

### Strategies you may want to try

It might be advisable to close the referral, let the GP know and push forward for a mental capacity assessment. This will allow for appropriate support arrangements to be in place, e.g., appointing a mental capacity advocate on the patient's behalf.

## **You realise that your patient may have dementia, but a diagnosis is not in place**

### Strategies you may want to try

Social prescribers have reported instances where they started working with a patient without a formal diagnosis of dementia, and then realised that actually they do not retain the information from previous consultations, or they may seem a little bit confused.

At the same time, it is very hard, especially when people reach a certain age, to know what normal forgetfulness or normal changes in behaviour is and what is actually a dementia concern. It is advised to refer the patient for a memory assessment, to initiate the process of getting a diagnosis, because that is the starting point to make them eligible for further support. Remember, no diagnosis equals no adequate support in place.

## **You realise that your patient may have dementia, but a diagnosis is not in place**

### Strategies you may want to try

Social prescribers have reported instances where they started working with a patient without a formal diagnosis of dementia, and then realised that actually they do not retain the information from previous consultations, or they may seem a little bit confused.



## You are unsure whether to use the word “dementia” or not

Strategies you may want to try

**Be aware that not every person living with dementia wants to hear/use the term “dementia”.**

In fact, in some language, the word “dementia” does not exist. Sometimes, you may read information in the patient’s referral (or notes) or have a feeling/doubt about whether it is appropriate to use the word dementia. It may be helpful to involve the caregiver or family of the person to learn about if and how dementia needs to be approached/discussed, if at all. Sometimes, to offer support, you do not need to use the word at all.

## The patient or the caregiver (family) refuses your support when you first contact them

Strategies you may want to try

**Consider offering a six-month courtesy call.**

Be aware that your patient (and their carers) may have been referred to you upon receiving a diagnosis and be still trying to absorb all the information and work out their grief: [alzheimers.org.uk/get-support/help-dementia-care/understanding-denial-lack-of-insight](https://www.alzheimers.org.uk/get-support/help-dementia-care/understanding-denial-lack-of-insight)

**Consider offering to send an information pack** via email or the post, with relevant information and contacts, so the person can get back to you in their own time. The info pack needs to have information accessible for both the person living with dementia and the carer, and always be up to date.



**Be aware that people living with dementia experience “rejection to care” –**

[scie.org.uk/dementia/living-with-dementia/difficult-situations/refusing-help.asp](https://scie.org.uk/dementia/living-with-dementia/difficult-situations/refusing-help.asp)

Also, their cognition fluctuates depending on days and times of the day. You may find it helpful to offer to call back on another day, potentially trying at a different time and/or to talk to a carer/family member. Sometimes, it might be helpful to use terminology a little bit differently to kind of fit the person’s needs, to kind of ease them in. For example, a patient may say that all they need is a cleaner. So instead of presenting yourself as a social prescriber, try to say you are there for the purposes of cleaning –

[alzheimers.org.uk/blog/lying-to-someone-with-dementia](https://alzheimers.org.uk/blog/lying-to-someone-with-dementia).

Ultimately, an initial “no” may not be definitive, so do not close the referral at first rejection, but try a couple of times more.

**You may want to consider that the original referral came at a point of crisis,** and by the time you make contact with the patient, the crisis may have resolved. Sometimes people just need to know there is someone if they need it.

**Try to describe your role** rather than saying the name of the role. A lot of people who hear the word social prescriber may confuse it with social worker or someone who prescribes medications.

**Ultimately, remember that you cannot impose support on anyone, so it is the patient’s decision whether they want to engage.**



## The patient does not remember they have been referred to you or having consented to the referral

Strategies you may want to try

**You may want to go back to the person who originally referred the patient** (e.g., GP) **to double check.**



### Munjal's story

## Making first contact with clients with dementia.

Munjal is a social prescribing link worker in a number of GPs in a large city in Northwest England. He has often finds that people with dementia struggle to engage in social prescribing, especially on first contact, which in most cases occurs over the telephone. Munjal shares some of his experiences and suggestions to address the challenges he faces at this stage of the support journey.

As a first step, Munjal observes that it is important to ensure that the client has capacity to consent:

*"We need consent to be able to go forth as there could be issues with mental capacity. If I see that could be the case, what I do is close the case and I let the GP know and I push forward for a mental capacity assessment. This would enable us to also address other support areas, such as appointing a mental capacity advocate on their behalf".*

In Munjal's experience, most clients with dementia show resistance to accept support or continue the conversation during that first call:

*"When I make the phone calls it's sometimes very dry at first and it's not going nowhere. They'd say - Oh, thank you very much, but we're alright. Thank you. Yeah. No, we're alright. We don't need anything".*





Munjal states that because of this resistance, there is a risk here to close the referral too early:

*"We may be actually closing the referrals for patients that could really benefit. For example, I call somebody, tell them I'm calling from the social prescribing to kind of discuss the service and they tell me I don't need anything. So, I close the referral, but then later I may receive a call from their sister. And they say - yeah, let's do this. I've got power of attorney - But those people that don't have the sister, they may not have that second chance if you close the referral there and then".*

There are some strategies that can help to explore whether client's resistance is genuine or a gut reaction. The first one is trying to arrange a home visit, if possible. It is Munjal's experience that showing up in person / multiple times can lower resistance from clients with dementia, when phoning in proves ineffective:

*"I had a client once who was not even picking up the phone. So, I went and knocked on the door and nothing. It was very close by, so I went a second, third time and eventually we got the person sat on that day. She was fine, totally fine, normal person talking".*

Another important tool to combat resistance is using clear and accessible language when giving information and explain social prescribing:

*"Describing your role rather than saying the name of the role can be helpful because for a lot of people when you say social prescribing the first thought is social worker. So, they think we're from adult social care. They get a little bit worried".*

Trying to establish contact or a communication channel with a family member prior to first contact could also prove very helpful, but it is important to keep in mind (and sometimes remind family members) that ultimately social prescribing is person-centred, and clients need to want to cooperate:

*"Unless someone has got power of attorney and the person is deemed not to have any capacity, I have to listen to what the client is telling me".*

Despite trying all different strategies, Munjal still finds that sometimes clients are resistant to engage in social prescribing. It is important to acknowledge that clients might not be ready to accept support, whatever the strategy you adopt you get them on board.





Munjal suggests that it might be helpful to:

*“Just close the referral. But I let them know that they can always come back to us if they change their mind in the future. Sometimes people just want to know there’s that someone if they need it”.*

In addition to reassurances that support is always available should clients need it, Munjal says it is also good to:

***“Send them out a leaflet that’s got all groups in the area and some links and it’s got a page that’s a bit of a checklist of things you might want to think about. And then we can schedule a six-month callback as well if they want it”.***

## 3 • Building trust and rapport

### **You are anxious that you may not be able to develop rapport with your patient**

Strategies you may want to try

**Try to establish an equal relationship,** conveying the message that you are a partner in care and that you and your patient are a team. Show them you are human, that you do not know everything about anything (e.g. saying “I don’t know what that is, but I’ll go and find it out with you and we will do some research together”).

**You may want to be aware that your first call(s) need to be longer** with a patient living with dementia. So be flexible and dedicate a good set of time to the call. Be open to have a bit of like a general chit chat first, to talk about different topics, and that you are actively listening to get the person engaged.



