

THE SCOTTISH DEMENTIA ALUMNI

Dementia & GP Services

A peer to peer resource
researched and written by people living with dementia



The Scottish Dementia Alumni

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The Scottish Dementia Alumni is a group of people living in Scotland with collective lived experience of a diagnosis of a dementia of almost sixty years.

The group was created to inspire and support people with a new diagnosis of dementia but also campaigns for human rights.

Each member has contributed to and/or written publications, made videos and has been cited in many publications.

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Introduction

This booklet was researched and written by the Scottish Dementia Alumni, a group of people who have lived with diagnoses of different dementias for several years. We are experienced campaigners who actively fight for the rights of people living with dementia.

Over the past decade, between us we have gained a Churchill Fellowship Award, two MBEs, a BEM, an Honorary Doctorate from Strathclyde University, a BA and a BSc, written books and booklets including the Self Management booklet, created and appeared in videos and have been referenced in many publications.

We received a grant from the Life Changes Trust, which enabled us to produce this booklet and the accompanying video.



We have experienced varying levels of service from our GP practices and noticed from conversations that others living with dementia had struggled to get appointments, adapt to online services and to receive an annual dementia review. We set out to research and discover what a GP practice should be providing. We will share our research widely in order to support others living with dementia to access quality GP services and to improve communication between people living with dementia and GP surgery teams.

Why We are Making this Booklet

'I have been trying to get through to my GP all week.' (twitter)

'The nurse rang and spoke at the rate of an express train. I said I have dementia I won't remember what you are saying.' (twitter)

'I'm quite lucky because... PCA is very rare and I see my consultant every six months for ever... also, the best bit is, I haven't got a link worker but the community nurse she comes every six weeks.' (interview)

'I have never had an annual review.' (interview)

'I'm quite happy with my GP, I get an annual review and I know the name of the nurse. I can phone up.' (interview)

You can see from all of these real experiences, that there is a need for clear communication around GP Practice services and that services in different areas and different GP practices vary.

We want to provide clear information to support people with dementia to confidently access GP services that they have a right to. We want to highlight the kinds of issues people living with dementia in Scotland are having so that GP Practice teams can help us.

What this Booklet is For

This booklet is to present clear information from our extensive research about what a GP service in Scotland should provide you with, as a person living with a dementia. We aim to offer clear reasons for the way GP services are changing in general, as well as through the Covid-19 pandemic, so that potentially frustrating changes can be clearly understood.

We hope that this booklet will help GP practices to better support people living with dementia by taking this information and providing clear communication to people living with dementia and care partners about available services, options for preferences in communication and how to access services.

This booklet is NOT offering any medical or legal advice. It is a general research - based guide to getting good access to your GP services.

This booklet will show you how we have navigated change. Change is inevitable and although we researched this information to be correct for December 2020, it will change. Please check with your GP and Health Board for updates.



Who this Booklet is For

This booklet is for people in Scotland living with dementia and for care partners to understand what a GP surgery offers in Scotland.

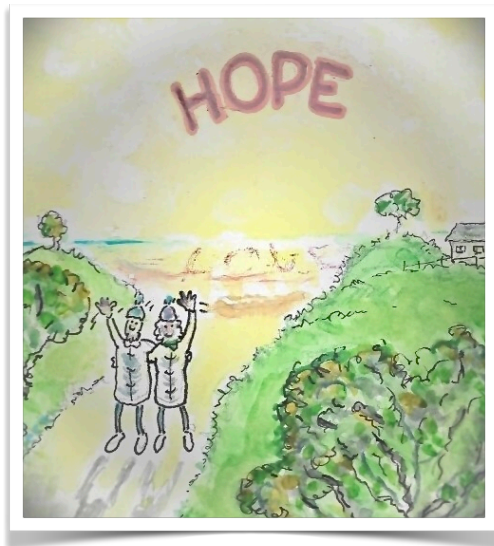
It is also for GP surgery teams to support them to understand more fully what people living with dementia need support with.

Our aims are :

To offer clear and well researched information, gathered together in one handy booklet to support everyone impacted by dementia in Scotland to have more confident access to GP services.

To support GP surgery teams to communicate with and serve people living with dementia in Scotland more confidently.

The reason that this booklet is only for Scotland is because other areas are organised and funded in different ways.



Refreshed Role of GPs

‘GPs are... a limited resource... There needs to be a balance between access to GP appointments, access to other health professionals where that is more appropriate, and encouraging patients to seek self-care advice, where appropriate. This will enable GP time to be available when really needed by patients.’

2018 General Medical Services Contract Scotland

This is what the General Medical Services Contract says about the way the role of the GP is changing to focus more on medical tasks and less on routine tasks or tasks that can be managed by other health professionals.

You can expect to see a whole range of health professionals so that your GP is still there for you when you need them.

Hospital at Home is a pathway some GPs can use to keep you out of hospital. See the resources page for details.

You can ask your GP about Social Prescribing. This is a way to support your mental health and well-being through arts and health based activities like art classes, yoga or gym membership.



Refreshed Role of the Practice Nurse

The General Medical Services Contract also details how the role of the Practice Nurse is changing. The contract promises more funding for the training of Practice Nurses and it states that one size does not fit all. Practice Nurses are not all the same. Some will have taken on specific training and have specialist knowledge but not all Practice Nurses will have the same skills.

What this might mean for all of us is that we might find our Practice Nurse prescribing medication and managing complex medical care cases with their new training. You might find that your Practice Nurse can now take on tasks that you used to see your GP for. It doesn't mean that you can't see your GP any more. It just means that your GP's time is being protected so that they will be available when you need them.

One GP surgery might have a dementia specialist nurse and another surgery might not. Some GP practices in Scotland partner up to form 'group practices', or clusters, where specialist nurses can be shared.



'I can prescribe your antibiotics.'
(GP nurse interview)

'I can call the doctor in if I need to.'
(GP nurse interview)

Refreshed Role of Practice Managers and Receptionists

In addition to continuing to manage the practice employed team, they will work more with the wider primary care system including GP clusters, NHS Boards, HSCPs, and emerging new services.

Alongside the changing role of practice managers, the roles of receptionists and other non-clinical staff in the practice have also evolved. www.gov.scot

Practice Managers need to have a broad set of skills to manage staff teams, IT systems, records storage and to work in partnership with many other health providers and teams.

Strategy implementation and planning are the kinds of high level tasks undertaken by Practice Managers. Your GP Practice website should state who the Practice Manager is if you need to contact them about something operational or you have a complaint.

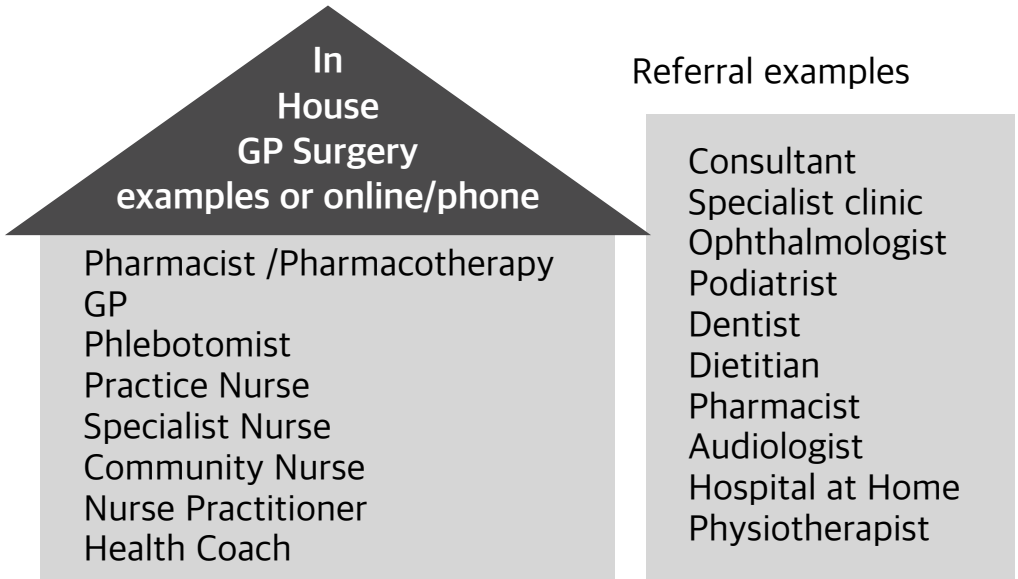
Receptionists need to have the correct information to support patients to access all of the services provided by the GP Practice. This person will most likely be your first point of contact with your GP Practice.

The receptionist will be recruited to be a good listener and communicator but they might not know you and it is important to be prepared for your call. If you have a list of key facts ready about why you are calling, the receptionist will be able to call you back or make you an appointment with the right person.

Multi Disciplinary Team

Your GP surgery team will direct you to the most appropriate team to help you. It might be an appointment at your own GP surgery, at a cluster surgery or at a clinic or hospital. Some rural areas might have more services available within their GP surgery, perhaps a pharmacy or specialist nurse shared with a cluster of practices.

Appointments might be in person or by video / telephone.



All these appointment types are part of local health services. Knowing what to expect is an important part of being prepared. Vaccinations (flu jab etc) are often managed by your local authority. You will receive a letter if you are eligible but if you are unsure, ask your nurse. Holiday vaccinations usually require you to pay a fee. Pharmacists can give you a medication review to check that nothing you are taking reacts with any medications.

GP Online Service

‘NHS Near Me’ is a service which can offer video outpatient appointments. You might be offered this kind of appointment. It is also known as ‘Attend Anywhere’.

You will need a computer or laptop, tablet, smart phone with a camera - a device which will connect you to an internet browser, Chrome or Safari. You will need a good internet connection and a quiet place to sit.

If you would like to try the service out in advance, you can practise with a test call through this website.

<https://nhsh.scot/nhsnearme>

The same kind of web platform can be used by GPs to offer appointments via video call.

If something goes wrong during a video appointment, don't worry because the GP can continue the appointment by phone if that is appropriate or they can rebook your appointment.

The Hospital at home service can offer some support to stay at home if this is appropriate.



Appointments in all Shapes and Sizes

Since the Covid-19 pandemic, many GP services started to use video software for appointments, telephone appointments and communication by email and text. It is important to recognise that this might not change back and will likely be offered as part of GP services going forward.

People living in remote areas, people who find it difficult to access the right care and support to attend a surgery and people with caring responsibilities, for example, might find it helpful to attend a video appointment.

If you don't find video or telephone appointments helpful, please let the person know when you make your appointment. They will be able to find you a suitable alternative, as it is your right to have reasonable adjustments made to suit your circumstances.

Your personal and medical information shared between services is protected. See the link on our References page.

'Ask about your annual dementia review because you might have it ticked off when you see your GP about something else.' (interview)

'My GP offered me a reasonable alternative' (Questionnaire)

Covid-19 Pandemic

Some things might look and feel different during Covid-19 and your GP service might be under more pressure. The important message is that GP services are there for all of your health needs. You should still get in touch with non Covid related problems so that smaller problems don't grow into bigger ones.

Your GP practice team are people too and are just as likely to become unwell or need to shield or self-isolate. This might cause staff shortages and/or the need for temporary staff.

You will likely still be able to go to your surgery when you are given an appointment but you are going to find changes like:

- * A one way system - perhaps arrows on the floors.
- * Hand sanitiser points.
- * Specific time slots so that waiting room time is reduced.
- * New spaced out seating arrangements in the waiting rooms.
- * You may need to stand behind a line on the floor to speak to a receptionist.
- * You will need to wear a face covering unless you are exempt.
- * You will need to socially distance as much as possible.
- * Additional cleaning. It might smell of cleaning products.
- * You might find a person to greet you and check your appointment time at the door to the GP surgery.



Conclusion

Your GP will be your first port of call for many of your medical needs but other routes are available to you to access all kinds of health care from urgent care to routine vaccinations.

Please see our resources page for links to videos.

In some areas, GP surgeries provide as an additional service:

Social Prescribing

Dementia review clinics

Named nurse for dementia

Specialist dementia nurse

Our research has highlighted variations in GP services in different areas and in different practices. We as a group are keen to take this forward and campaign for equity of services for dementia.

Human Rights Approach

It is our right to receive quality GP services for our dementia.

Not more than diabetes or heart disease but equal to.

These rights need to be upheld not as a 'should' or 'could' but as a quality standard that we can expect.

We have the right to life.

We have the right to liberty.

We have the right to a family life.

We have the right to live free from discrimination.

We have the right to reasonable adjustments to services.

Our Campaign

The term 'Dementia Friendly' is not always helpful. We are talking about human rights to quality care from our GP services. Other health conditions are prioritised with comprehensive annual reviews (diabetes, heart disease etc.) but not always dementia. GP services for dementia vary from area to area and practice to practice.

Some GP practices offer better services for dementia through funds allocated to a group of practices but this is by choice.

What we will campaign for as a result of our research:

We would like to see:

- Our human rights upheld.
- GP practices offer standard, high quality, dependable services to everybody living with a dementia.
- Equal (equitable) and fair services.
- A service that is not funded unless it is delivered effectively.
- An annual comprehensive review for everybody with a dementia and mild cognitive impairment.
- An effective method of triage for appointments.
- A named nurse for dementia in each practice.
- Effective communication.
- Reasonable adjustments made for dementia.
- Social Prescribing for wellbeing.

GP Checklist

A GP gave us a checklist for a dementia check up/review.

1) What specific difficulties are you having in day to day activities (cooking, personal hygiene, finances, managing medicines etc. or anything that is important to you).



2) What keeps you well?



3) What matters most to you?

4) Support systems/social connection: Family, Friends, Neighbours, Community organisations, places of worship etc.



5) Do you have any thoughts, wishes or plans about the future that you want to discuss, particularly if you become unwell, future care, hospitals etc?



6) Do you have a power of attorney?



Our Additions to the GP Checklist

Our own research highlighted two further issues:

7) Hydration. Are you drinking enough fluids?



8) Have you made plans for DNR status or organ donation? (See our link to Future Care Planning at the back of this booklet).

These are issues which require thought in advance so that you aren't feeling under pressure to make quick decisions. Nothing related to DNR and organ donation should have changed through Covid-19. You have the right to take your time to plan your decision-making with appropriate support and information.



'I have no idea if my surgery offers online appointments. I had a DNAR form in the post from the GP but I don't know what it means.' (Interview)

Helpful Resources - Click Links

[Zoom Guide from Innovations in Dementia](#)

[NHS Near Me Leaflet from NHS Highland](#)
[NHS Near Me Scotland Website](#)

[Citizens Advice Bureau Guide to Human Rights in Healthcare](#)

[NHS Inform Scotland](#)

[Scotland's Service Directory](#)

[Anticipatory Care Planning](#)

[Power of Attorney Information](#)

[Attend Anywhere Video](#)

[How to Access Urgent Care](#)

[Hospital at Home](#)

[Dementia and Self-Management - Scottish Dementia Alumni](#)

COVID-19 RELATED LINKS

[NHS GP Video During Covid](#)

[Dental Care Video During Covid](#)

[Scottish Government Dementia and Covid-19 Action Plan](#)

References

A Guide to making GP Practices Dementia Friendly -
Alzheimer's Society & Alzheimer Scotland

Focus on Improving Diagnosis and Post Diagnostic Support
For People With Dementia.
Healthcare Improvement Scotland

National Dementia Strategy 2017-2020
Scottish Government

A Quality Improvement Framework For Dementia Post
Diagnostic Support in Scotland
Healthcare Improvement Scotland

The 2018 General Medical Services Contract in Scotland

Shaping the Future Together
Report of the Remote and Rural General Practice Working
Group Scottish Government

Our Dementia Our Rights
The Dementia Policy Think Tank & Innovations in Dementia

Joint statement on Advance Care Planning

Freedom of Information responses

Social prescribing in Scotland [http://
www.healthscotland.scot/publications/social-prescribing-
resources](http://www.healthscotland.scot/publications/social-prescribing-resources)

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The DEEP Network.

Innovations in Dementia.

Life Changes Trust.

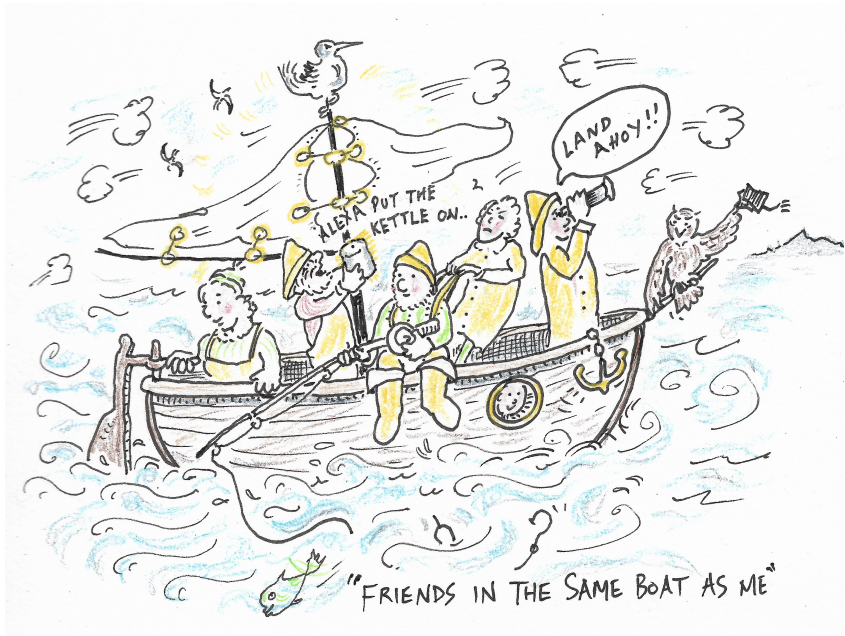
Friends on social media.

Mission Dementia.

GPs, Practice Nurses and Pharmacists who contributed.

Our friend and Artist Paul Thomas.

Our Facilitator Paula Brown.



Notes:



Your GP Surgery:.....



Your phone number:.....

Your date of birth:.....

Your email address:.....

Do you have any allergies?.....

Glossary and Common Acronyms

BA - Bachelor of Arts (degree)

BEM - British Empire Medal

BSc - Bachelor of Science (degree)

CMHT - Community Mental Health Team

CPN - Community Psychiatric Nurse

DEEP - UK Network of Dementia Voices

GP - General Practitioner

GPCOG, MMSE - tests for diagnosis of dementia

HSCP - Health & Social Care Partnership

MBE - Member of the British Empire

NHS - National Health Service

OOH - Out of Hours Service (weekends/night)

PCA - Posterior Cortical Atrophy

DNR - Do Not Resuscitate

DNAR - Do not attempt resuscitation

DNACPR - do not attempt cardiopulmonary resuscitation

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The UK Network
of Dementia Voices

