

Resource Pack for Families and Carers

Understanding Behavioural and Psychological Symptoms in People Living With Dementia

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Introduction

This resource pack has been designed to support families and carers of people living with dementia, who experience behavioural and psychological symptoms (non-cognitive symptoms) of dementia (BPSD).

The pack sets out the typical causes of BPSD and ideas for managing it.

It also provides sources of further information and support; including resources for capturing behaviours, their severity and frequency, to help determine the triggers and inform other health professionals.

BPSD is an abbreviation which is often used instead of the full phrase “Behavioural and Psychological Symptoms of Dementia”.

If you are caring for someone with dementia, ensure that your own GP is aware of your responsibilities. There may be additional sources of help and support for you.

Everyone’s experience as a carer is different, and you are likely to find that some of the suggested approaches may be more helpful and effective than others.

Financial support may be available for the carer and for the person with dementia, and advice can be given by the Citizens Advice Bureau or your GP surgery, if they have a social prescribing service.

What is BPSD?

More than 90% of people with dementia will experience BPSD (Behavioural and Psychological Symptoms of Dementia) at some time during their illness, particularly in the middle and later stages. Many of these symptoms may be the person's response to their own thoughts, the environment, and their physical health, and sometimes there may not be a clear trigger.

- **Behavioural symptoms** include physical aggression, loud vocalisation, restlessness, agitation and wandering. People may also develop a change in their taste and food preferences (e.g. they may start to prefer sweet items) or adopt particular habits; and there may also be changed behaviours in public.
- **Psychological symptoms** include anxiety, depressive mood, hallucinations and delusions.

Hallucinations are where someone may hear, see, smell, taste or feel things that appear to be real but only exist in their mind. Be careful that long term memories are not interpreted as hallucinations by people who are not aware of events in the past.

A delusion is a belief held with complete conviction, even though it's based on a mistaken, strange or unrealistic view. It may affect the way the person behaves. Some people who experience delusions find different meanings in everyday events or occurrences. They may believe people on TV or in newspaper articles are communicating messages to them alone, or that there are hidden messages in the colours of cars passing on the street.

Understanding and managing BPSD

This section explains why a person with dementia might demonstrate behavioural and psychological symptoms and identifies many of the typical causes of BPSD. It provides ideas on how to manage the symptoms and support the person with dementia. Ideally, approaches other than medication should be used first for managing BPSD. However, at some point the GP or other specialist may feel that prescribing medication would be the best option for that person, combined with other approaches.

As well as support from the person's GP and other specialists involved in their care, there are several organisations that may also be able to provide support and advice to the individual or to those people caring for them. These are set out on pages 30 to 34.

These organisations can support families and carers at all times – it is often helpful to make contact with such support early on, so that appropriate help can be given at the right time.

Carers of people with dementia may experience stress and burnout – it is important that appropriate help and support is sought, from either their GP or support networks listed at the end of this booklet. Carers are entitled to a carers' assessment of the carers' needs – contact details for social services are included on page 34.

Carers and family members should be alert to risks and consider seeking advice on setting up Powers of Attorney at an early stage to provide help in managing the person's health and financial affairs. Some organisations may make a charge for this service. Page 34 includes details of organisations which may help.

Behavioural and psychological symptoms of dementia are an active attempt by the person with dementia to meet or express a physical or psychological need.

For example, agitation may be communicating boredom, anxiety, embarrassment or it may be a response to pain or discomfort or an environmental challenge e.g. noise.

In this pack typical causes for distress and BPSD are broken down into 5 areas and set out in tables:

1. Physical health and medication side effects
2. Environmental factors
3. Lack of acceptance of the person's beliefs and life-style preferences
4. Lack of understanding of how the person sees and interprets their world
5. Underlying emotional or mental health problems

Each table provides ideas for families and carers to help manage or alleviate the distress for the person with dementia.

If the difficulties are not resolved with the suggestions provided, or you are worried about the person with dementia, or yourself, it is important to contact their GP Surgery or primary care team for help.

Doses of medicines should not be altered without advice from the clinician involved in their care.

1. Possible cause: Physical health and medication side effects

BPSD may result from:

Pain resulting from numerous causes e.g. joint, dental problems, discomfort from skin problems, constipation, infections.

NB: People with dementia are often not able to identify or may deny pain due to their cognitive impairment or communication difficulties.

Pain is often undiagnosed and undertreated.

Ideas for family and carers:

Look out for any pain response during personal care tasks and when the person moves – for example from a bed to a chair, or takes a walk.

Ask the GP surgery to review in case treatment is needed for pain relief.

Pain may arise from dental issues, which should be reviewed by a dentist.

Sleep disturbance - may be a symptom of dementia or a medication side effect

Is the person getting any exercise, are they sleeping too much during day, are they under stimulated? (See page 11 for ideas on stimulation)

Consider exposure to daylight, exercise, and personalized activities

A good night's sleep is also important for carers. Some useful tips are given on the NHS website -

<https://www.nhs.uk/conditions/insomnia/> and the GP should also be made aware of the carer's difficulty sleeping

1. Possible cause: Physical health and medication side effects

BPSD may result from:

Physical limitations:

for example - hearing, eyesight, bad feet/nails

Ideas for family and carers:

Is the person using their glasses or hearing aids? However, it may be difficult to resolve hearing or sight difficulties if the person is unable to understand or may resist the hearing or sight tests. It may be possible for the person's usual optician to visit at home.

Have the hearing aids been checked, and are the batteries still working?

Does everyone caring for the person know if they have difficulty hearing in one or both ears, or difficulty with their vision?

Are the feet and nails in good condition and not likely to be a cause of discomfort?

If the person develops urinary or bowel incontinence, a local NHS continence service will be able to supply advice and access to support. In some areas of the county you will need to be referred by your GP surgery.

1. Possible cause: Physical health and medication side effects

BPSD may result from:

Ideas for family and carers:

Medication side effects

Request a review of medication by a pharmacist or GP

Infections – Urinary tract infections (which can cause confusion), thrush, chest, skin infections, cellulitis.

Some signs of infections can include:

A high temperature

Urine that looks cloudy, dark or has a strong smell; if needing to pass urine more urgently or more frequently than usual

Hot, red, and swollen areas of skin, or painful lumps or bumps.

A cough, possibly with yellow or green mucus (phlegm)

Call 111 or their GP if you are worried about the person, and you think that they might have an infection

CALL 999 if:

The person is struggling to breathe

They have pale, blue or blotchy skin, lips or tongue

The person is unusually drowsy

1. Possible cause: Physical health and medication side effects

BPSD may result from:

Hunger, thirst, dehydration and swallowing difficulties. If swallowing difficulties develop, these should be discussed with the person's GP surgery.

Ideas for family and carers:

Check the person's access to food and fluids and ability to eat and drink independently.

Is the person able to eat and drink? e.g. denture pain / mouth ulcers / ability to use cutlery. Offer support as needed.

Are their own dentures available and well fitting, or own teeth in a good state? Regular dental check-ups are important to treat and prevent any problems.

Use their personal preferences for food, drinks, crockery etc. – for example, a favourite mug, preferred time to eat a hot meal, some people prefer food that can be eaten with fingers rather than cutlery. Let the person eat what they want.

Taste and preferences often change for people with dementia. Try to identify what tastes and textures are preferred and check periodically.

More information is available from Dementia UK (Eating and drinking for a person with dementia).

2. Possible cause: Environmental factors

BPSD may result from:

Ideas for family and carers

Under stimulation

Encourage the person to continue with interests or hobbies; they may also find enjoyment in new activities.

Provide – opportunities for conversations and chatting with other people.

Identify social opportunities, to encourage interactions with others. A shared diary or Whatsapp® group with friends and family may help to identify times when extra support may be welcomed.

See pages 30-34 for links to support services and organisations that can help with finding dementia friendly activities and day services in your area. The Surrey Dementia Roadmap provides details of various day centres, support groups and carers' forums across Surrey.

<https://dementiaroadmap.info/surrey>

2. Possible cause: Environmental factors

BPSD may result from:	Ideas for family and carers
Overstimulation	The person may get agitated if too many people around, too noisy or after lunch if they are tired. Some people with dementia find social occasions or large groups very stressful as they may be confused, or may not understand what people are saying. Consider quiet time, an afternoon nap (but avoid long naps to avoid impacting sleep at night), sitting in a garden or with calming music.
Are all the family members or carers aware of factors or situations which could make BPSD worse?	Capturing information can help families to manage / avoid situations; it can also be useful to share with healthcare professionals when determining the best course of action. A sample form and worked example can be found on page 22.

2. Possible cause: Environmental factors

BPSD may result from:	Ideas for family and carers
<p>Reactions to uncomfortable temperatures</p>	<p>If the person feels too warm, consider increasing fluids, the use of fans or sitting outside in a garden</p> <p>If cold use blankets and extra clothing.</p> <p>At extremes of weather (very hot or very cold) support the person to follow any national safety warnings.</p> <p>Make sure there are no open sources of heat that the person could try and use if they are not safe to do so (e.g. open fires). Take care with hot water bottles.</p> <p>Make sure the heating system is working correctly and timers set appropriately. Be aware that accessible timers may have been changed by the person with dementia; they may have inadvertently turned the heating on / off.</p>
<p>Getting used to a new place to live</p> <p>It may take up to 6 weeks for people to feel settled in the new environment</p>	<p>Make sure that family members and/or previous carers share ideas and suggestions of what has helped in the past.</p> <p>Make sure they have their personal belongings in their new room</p> <p>Where possible, try to ensure that established routines are introduced at the earliest opportunity when a person moves home.</p>

2. Possible cause: Environmental factors

BPSD may result from:

Ideas for family and carers

The physical design of the home

Make sure there is good lighting, with nothing blocking the light coming in through the windows. Ensure that the bedroom is dark enough at night to allow a good night's sleep.

Use bright and contrasting colours to help the person see furniture better, but avoid stripes and strong patterns as they can cause confusion. Consider removing the toilet lid if it makes it easier to identify.

Check for any rugs or cables which could cause trips and falls.

Put pictures or signs on cupboards and drawers, and try to keep things like keys, wallet and mobile phone in the same place.

Make sure that any smoke alarms or carbon monoxide detectors fitted in the person's home are working. The Fire and Rescue service can undertake a home visit to advise on safety.

3. Possible cause: Changes in ways of expressing views and opinions.

BPSD may result from:

Lack of understanding of their current beliefs and preferences (which may change during the course of the dementia).

Ideas for family and carers:

Consider using life story templates e.g. 'This is Me' (from the Alzheimer's Society) to gather information so that everyone involved in the person's care knows what is important to the person. Other examples are on pages 28-30.

Acknowledge where the person is at – don't argue or attempt to correct them, or change their viewpoint. The family or carer may need to explain to others that the person's views are not long-held but are affected by their illness, and that no offence is intended.

Unless the person is doing something unsafe, try to accept that whatever they are expressing is the truth to them at that point in time. Trying to do this is very hard but can avoid confrontation and make a huge difference to the happiness of the person and the carer.

Consider distracting the person by offering meaningful activity (see section on stimulation, page 11) to lessen confrontation.

3. Possible cause: Changes in ways of expressing views and opinions.

BPSD may result from:	Ideas for family and carers:
Lack of understanding of the person and their current beliefs and preferences.	Be aware of religious or cultural rules and customs. Check the person's attitudes towards physical touch Try to ensure that all family members have the same information to inform care and better understand the individual
Lack of understanding of the person and their current beliefs and preferences.	Using the Hidden Disabilities Sunflower lanyard can be a useful way to explain to other members of the public that a person has dementia. https://hiddendisabilitiesstore.com/us/ .

4. Possible cause: Impairment in communication (hearing, vision, speech)

BPSD may result from:	Ideas for family and carers:
The person becoming unable to communicate their needs or requests are being ignored.	<p>Be proactive with checking the person's needs at frequent intervals. watch their face and observe their body language.</p> <p>Use short simple sentences or statements or non-verbal gestures to indicate walking to toilet, etc.</p> <p>Use picture boards</p>
Hearing and visual difficulties.	<p>Check which is their 'best' ear, or if they have visual impairment on one side then approach from the other</p> <p>Continue seeing the Optician (most opticians offer home visits if needed).</p> <p>Ensure hearing aids are regularly cleaned and checked, and the batteries are working. Continue to attend audiology appointments.</p>
Difficulties in recognizing everyday objects	Use alternative means to aid recognition - labels, prompts, or pictures. The family member or carer may need to demonstrate use of the object.
Repetitive behaviours	Use other activities to distract the person, as well as reassurance. See the section on under stimulation on page 11.

4. Possible cause: Impairment in communication (hearing, vision, speech)

BPSD may result from:	Ideas for family and carers:
<p>Changed behaviours in public which may be offensive to others.</p>	<p>Try to distract the person with activities or conversation and alternative means of meeting their needs.</p> <p>Try to note if there are particular times of day or triggers. If possible, plan enjoyable activities around these times.</p> <p>If the behaviours become risky or unpleasant for others to see or hear, then speak to their GP surgery.</p>
<p>Experiencing delusions and visual hallucinations:</p>	<p>Take personal care tasks slowly and give repeated reassurance about intentions.</p> <p>Acknowledge the delusion / hallucination – don't ignore or try to prove to the person they are wrong.</p> <p>If they are not concerned or anxious about it, then don't dwell on it.</p> <p>Ensure plenty of reassurance if the person is worried and ensure there are alternative activities to be involved in.</p> <p>If concerned, speak to the person's GP surgery. They may consider referral to specialist services for further assessment/treatment.</p>

5. Possible cause: Underlying emotional or mental health problems

BPSD may result from:	Ideas for family and carers:
<p>Undiagnosed depression and anxiety</p> <p>The person may be searching for their loved ones.</p> <p>Experience of bereavement or effects of traumatic events in their life</p>	<p>Depression is a common occurrence in people with dementia. If you are concerned about the person's mood, ask their GP surgery for advice.</p> <p>Ensure the person has access to activities and encourage participation; Where possible, promote active involvement of friends and relatives.</p> <p>Be aware of situations which cause anxiety and try to avoid or change these if possible. Try to provide the person with a sense of control and safety through explanation and reassurance.</p> <p>If they are looking for a friend or family member, it may be best to suggest where the loved one might be (e.g. out at work, gone shopping).</p> <p>Enable usual activities, e.g. safe walking and make the most of the person's strengths and remaining abilities.</p> <p>Consider using dolls, music therapy and massage. If the person is accustomed to pets, they may help relaxation.</p> <p>Share with other family members and carers what works.</p>

5. Possible cause: Underlying emotional or mental health problems

BPSD may result from:

Loss of sense of direction, time, or location

Ideas for family and carers:

The DVLA (Driver and Vehicle Licensing Agency) must be told if the person has dementia. With consent, the DVLA may ask the person's doctor for a medical report to decide if they are safe to drive. If the doctor asks the person to stop driving at any time, they must do so straightaway. If family or carers are worried about the person driving, they can contact the DVLA.

More information is available from <https://www.gov.uk/dementia-and-driving>

The person must also tell their insurance company that they have dementia.

Many mobile phones have a 'Find my phone' facility, or a wearable 'tracker' might be considered. Using these devices could prolong the person's independence while providing reassurance to carers.

Completed Sample - Family / Carer completed non-cognitive symptom (BPSD) recording form for people living with dementia (Sample)

1. Describe the behaviour(s) that concern you as a carer in the first column.
2. At the end of each day, put the appropriate code in the column and make a comment if you wish.
3. Ideally the same person should complete the form each day.
4. Use an additional form if necessary.

Column codes

- A. Not a problem today
- B. A problem but manageable
- C. Finding it difficult to cope

Symptoms	Date												
	16/02	17/02	18/02	19/02	20/02	21/02	22/02	23/02	24/02	25/02	26/02	27/02	28/02
<i>Hitting out when trying to wash and dress him.</i>	A	B	A	A	B	B	A	B	B	A	A	A	B
<i>Shouting loudly and unexpectedly for no apparent reason.</i>	A	A	A	A	B	A	A	A	B	B	A	A	B

Date	Comment
17.02	<i>Agitated after breakfast when washed but calmed down later.</i>
19.02	<i>Really calm today.</i>
20.02	<i>Dad was discovered to have a temperature and once given some paracetamol he calmed down.</i>
23.02	<i>Still on regular paracetamol</i>
24.02	<i>Paracetamol stopped after lunch and temperature stayed normal. More agitated than normal though.</i>
25.02	<i>Medicines were adjusted by GP</i>
26.02	<i>Really calm today and more alert but calm.</i>
28.02	<i>A bad day today but manageable.</i>

Blank - Family / Carer completed non-cognitive symptom (BPSD) recording form for people living with dementia

Name

1. Describe the behaviour(s) that concern you as a carer in the first column.
2. At the end of each day, put the appropriate code in the column and make a comment if you wish.
3. Ideally the same person should complete the form each day.
4. Use an additional form if necessary.

Column codes

- A. Not a problem today
- B. A problem but manageable
- C. Finding it difficult to cope

	Date												
Symptoms													

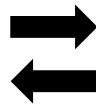
Date	Comment

Sharing information on the person with dementia's needs, interests behaviours and preferences.

These pages may be helpful if the person with dementia receives care from several different people, so that everyone is able to provide similar ways of helping the person if they are experiencing BPSD.

How I present when I am well...

Early warning signs that I am becoming distressed

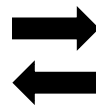


You can help me by...

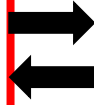
You can help me by...

Please help me to avoid...

Please help me to avoid...



**How I present when I am
really distressed...**



**How I present after an
episode of distress...**

You can help me by...



You can help me by...

Please help me to avoid...

Please help me to avoid...

My name

All about me

Communication Tips

Photograph

Strengths and things I am proud of

I like to be called

My preferred routines

Things that interest me

Things that worry or upset me

**Important objects /activities that help
me cope or calm down**

When I say or do this

it usually means

Further Sources of advice and guidance

Dementia Connect – Contactable through

<https://www.alzheimers.org.uk/get-support/dementia-connect> or

call **0333 150 3456**

Support line opening hours

- Monday – Wednesday 9:00am – 8:00pm
- Thursday – Friday: 9:00am – 5:00pm
- Saturday – Sunday: 10:00am – 4:00pm

Alzheimer’s Society Website www.alzheimers.org.uk – offers

signposting to local services, some of which are run by the

Alzheimer’s Society, and contains a wide selection of fact sheets; e.g.,

- Changes in Behaviour
- Challenging Behaviour in Dementia
- Staying healthy with sleep
- How to support someone with dementia to sleep better at night
- “This is me” document
- When should drug treatments be prescribed for people with dementia?
- Preventing and managing aggressive behaviour

Age UK have a variety of services, activities and events available

across Surrey, including opportunities for people to join in a range of

fun and stimulating activities including lunch clubs. For more

information visit: www.ageuk.org.uk/surrey or telephone: 01483

503414. For people living in Hampshire, Age Concern Hampshire is

an independent registered charity working to support the ageing

journey of older people in the county. They can be contacted via

<https://www.ageconcernhampshire.org.uk/> or on [01962 868545](tel:01962868545).

Dementia Carers Count <https://dementiacarers.org.uk/> offers a range of free services that give family carers the opportunity to understand more about dementia and to connect with others in a similar situation. They offer practical advice on the reality and challenges of being a carer. They provide free online learning sessions for carers.

Connect to Support Surrey <https://www.connecttosupportsurrey.org.uk/> is a resource that has been developed with partners to help local residents, and professionals working across health and care, access essential information about care and support.

Dementia UK is a charity committed to improving quality of life for all people affected by dementia. <http://www.dementiauk.org>
Families living with dementia can access life-changing support from a dementia specialist Admiral Nurse, at a dedicated time and place that suits their needs. This can be via the helpline 0800 888 6678 Monday to Friday 9am to 9pm Saturday and Sunday 9am to 5pm. Some areas have a locally-based Admiral Nurse; the helpline can advise about this. Appointments are free and confidential.

Admiral Nurses have the time to listen and the knowledge to solve problems. They can help with any questions and concerns about dementia, including:

- understanding the diagnosis, plus practical tips and advice for caring for a loved one with dementia
- transition into nursing or residential home, or stays in hospital
- understanding symptoms and changes in behaviour, and managing your own feelings

Younger People With Dementia www.ypwd.info (Surrey Heath, Farnham and NE Hants) provides age-appropriate and meaningful workshops, micro-groups and 1 to 1's across the working week for those diagnosed with young onset dementia. They run an education course for carers and the person with dementia (in different rooms simultaneously), and has a carer support group and social events.

Action for Carers is a third sector organization that offers an array of services across Surrey. They can help carers engage in carers assessments, apply for eligible benefits and access support groups. They can also offer peer support. The Carer Helpline is available on 0303 040 1234. Text on (SMS) 07714 075993. Send an email to CarerSupport@actionforcarers.org.uk

- Monday, Thursday, Friday – 9-5pm
- Tuesday, Wednesday – 9-6pm

The Surrey Dementia Roadmap

<https://dementiaroadmap.info/surrey> - provides high quality information about the dementia journey alongside local information about services, support groups and care pathways to assist primary care to support people with dementia and their carers.

Rare Dementia Support (RDS) is London-based, but has regional support groups and also offers webinars. Their website is <https://www.raredementiasupport.org/>. The support offered by the RDS regional groups can range from small discussion groups, where members can talk about whatever they would find most helpful, to larger speaker-led talks on a range of subjects. They provide an

opportunity for carers of those living with one of the rare diseases supported by RDS — Frontotemporal dementia, Primary Progressive Aphasia, Posterior Cortical Atrophy, Lewy Body Dementia and Young-onset Alzheimer's Dementia — to meet others in similar situations and discuss their experiences and concerns in a relaxed setting. RDS Specialist Support Team can be contacted via contact@raredementiasupport.org or on 020 3325 0828

The **Hampshire Carer Support and Dementia Advice Service** is provided by Andover Mind. The service is available to anyone with a diagnosis of dementia, people with suspected dementia to help support them through the diagnostic process and carers over the age of 18. Andover Mind can be contacted on 01264 332297 Press option 3 for the Carer Support and Dementia Adviser Service. Their email is enquiries@andovermind.org.uk

Connect to Support, Hampshire provides resources to help residents in Hampshire stay safe, care for themselves and connect with the local community. <https://www.connecttosupporthampshire.org.uk/>

Power of Attorney Services A lasting power of attorney (LPA) is a legal document that allows someone to choose a person (or people) they trust to act on their behalf if they are no longer able to make their own decisions. A number of different organisations offer a lasting Power of Attorney Service. Some may charge for this service. Information is available via the NHS website -

<https://www.nhs.uk/conditions/dementia/legal-issues/>, and organisations such as Age UK, and the Alzheimer's Society.

Social Care Services aim to help people stay independent, safe and well so they can live the lives they want to. This includes people who are frail, have disabilities, mental health issues as well as the people who care for them. Short term help may be offered, and options for longer term support if people have more complex needs.

Surrey County Council Adult Social Care (surreycc.gov.uk/adults)

Information and advice is available online or 9am to 5pm, Monday to Friday by contacting:

- **Telephone:** 0300 200 1005
- **Email:** asc.infoandadvice@surreycc.gov.uk
- **Textphone (via Text Relay):** 18001 0300 200 1005
- **SMS:** 07527 182 861 (for the deaf or hard of hearing)
- **VRS:** [Sign Language Video Relay Service](#)

Hampshire County Council Adult social care resources and signposting is available via

<https://www.hants.gov.uk/socialcareandhealth/adultsocialcare> or by telephone: 0300 555 1386

Monday 8.30am to 5pm

Tuesday to Thursday 9.30am to 5pm

Friday 8.30am to 4.30pm.

Outside of these hours - 0300 555 1373

Choice and Medication – this website provides information leaflets on medicines, and a series of information leaflets on dementia and Alzheimer's disease. <https://www.choiceandmedication.org/sabp/>

Electronic Medicines Compendium – www.medicines.org.uk for prescribing information and manufacturer’s patient information leaflets

National Institute for Health and Care Excellence (NICE) If there is a suggestion made that medication may be prescribed for the person, the NICE Decision aid – “[Antipsychotic medicines for treating agitation, aggression, and distress in people living with dementia](#)” may provide some help for families and carers to understand the reason for prescribing medication, and to participate in a decision as to whether it is appropriate for the person.

Books

“Reading Well - Books on Prescription for Dementia” recommends books you might find helpful if you have dementia, are caring for someone with dementia or would like to find out more about the condition.

The books provide information and advice, support for living well, advice for relatives and carers, and personal stories. They are endorsed by health professionals and can all be found in the local library.

Selected titles are also available to borrow as e-books and audiobooks. [Visit your local library website](#) to find out how to join the library and access books electronically.

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and Surrey Heartlands Health and Care Partnership*

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