

NHS Solihull <u>Clinical Commi</u>ssioning Group

# Dementia Information Pack













Increasing Care (Including End of Life Care)

# Section 1: Introduction

# How to use the Dementia Information Pack

Alzheimer's Society has produced a <u>national Dementia Guide</u>. It contains all of the information that people with dementia and their families and carers think will be useful to help you to live well with dementia. This pack provides the local perspective on that information and sets out the services and support available to you in Solihull.

Every person's journey with dementia will be different and so a key part of this information pack is the stories and experience section where people have been encouraged to tell us what they struggled with and what they have found really helpful. We want this pack to keep evolving with the changes to dementia services in Solihull. We want to encourage you to tell your story so that we can continually improve the services that are available within Solihull and for your story to help other people being diagnosed with dementia.

In producing this pack we had long discussions about how we would inform you about the "dementia pathway" so that you know what is available by way of support at different stages of your journey with dementia. We decided to articulate this as "Eileen's Journey" and hope that this will better guide you in getting the help and support that you need. We have also tried to describe what we think would be the ideal journey for some who cares for someone with a diagnosis of dementia. This is called 'Jack's Journey'.

We know that dementia is not a diagnosis that you would want to get but we hope that in using this pack you and your family will have the support that you need to live well with dementia. There is a lot that can be done to help you and your family and this includes:

- Access to dementia advisers who will help you find the information, advice and support that you need.
- Specialist therapies such as "cognitive stimulation therapy" and "self-management and memory group".
- Training for families and carers in helping them to better understand dementia such as the "Caring in Dementia Group".
- Help and support for carers identified through an assessment of the needs of carers.
- Dementia medication which may prolong the time before the dementia worsens.
- Monthly Alz Cafes which provide information and advice to people with dementia and their families.

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- Memory Café a peer support group which is led by people with dementia and supported by the Alzheimer's Society staff.
- Having fun singing for the brain, tea dances etc. More is being done to broaden the wider community activities available for people with dementia to access and when these are developed the details of these activities will be sent out to you.

Information about all of the above is included within this pack.

In the <u>stories and experiences section</u> of the pack you will be able to read Tony's story. Tony's story will show you that getting a diagnosis of dementia brings with it opportunities to make new friends through the memory café. The memory café is where people with dementia help and support one another, go out on trips that they have planned, bring in specialist speakers and more importantly just have a laugh. It is really important to us that you have good experiences like Tony and hopefully this guide will help you do that.

This Dementia Pack provide information on topics of common interest but it may not answer your specific queries or concerns. Further information and support is therefore available as follows:

- Should you require further information regarding the medical aspects of your condition then you should ask for a follow-up appointment with the Memory Assessment Service (MAS) assessor by ringing 0121 301 5440.
   For other medical issues contact your GP.
- For more information and advice on how to live well with dementia and onward signposting to the most appropriate support services please contact the Alzheimer Society and talk to a Dementia Adviser. The number for the local office is **0121 706 4052**.
- For support from Solihull Council's Adult Social Care Team please ring 0121 704 8007.

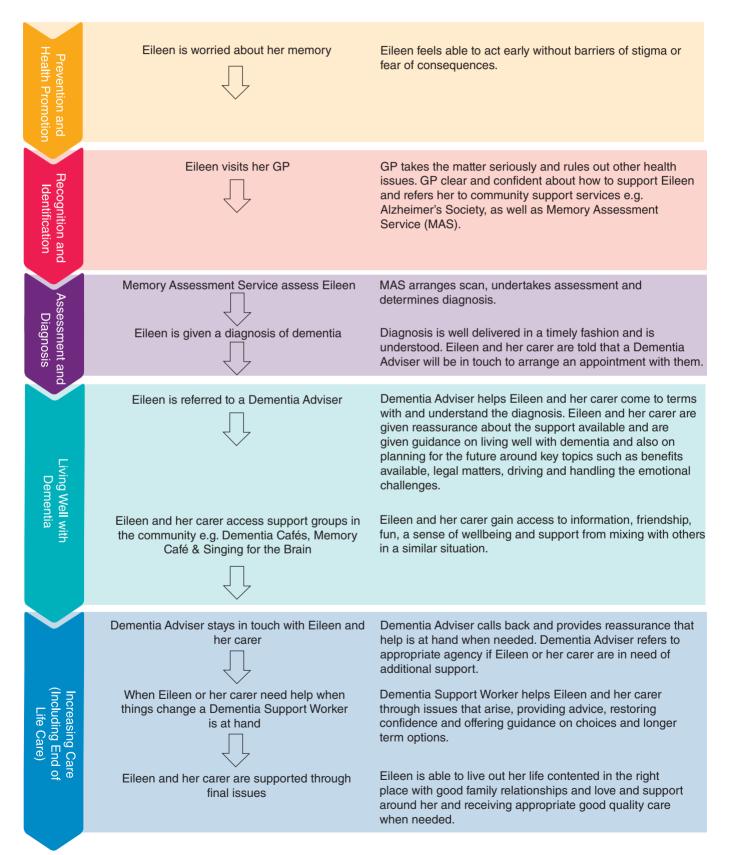
# Your Feedback

We hope that you will find the information in this pack useful but we also want to know if there are ways we can improve the pack and we need your help to do this. Please let us know what you have found useful in the pack and if there is anything we have forgotten to include. We would also like to hear about your good experiences of living with dementia, or any difficulties you may have encountered.

<u>Please use this online form to give us your feedback</u>. All your comments will go to Solihull Council's Commissioning Team.

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# Section 2a: Eileen's journey



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# Section 2b: Jack's journey

Prevention and Health Promotion	Jack is worried about the memory of his wife, Eileen.	Jack has seen awareness campaigns about dementia and knows that he should contact their GP.
Recognition and Identification	Jack goes with his wife to see the GP.	GP takes the matter seriously and rules out other health issues. GP is clear and confident about how to support Eileen and refers her to community support services e.g. Alzheimer's Society, as well as Memory Assessment Service (MAS).
Assessment and Diagnosis	Memory Assessment Service (MAS) assess Eileen Jack is with Eileen when she is given a diagnosis of dementia.	MAS arranges scan, undertakes assessment and determines diagnosis. Jack is encouraged to contact the Council's Connect Team to find out about having a Carer Assessment.
d Living Well with Dementia	Jack chooses to have a Carer Assessment.	Jack's support needs are assessed. Jack is informed about services that are available that can offer him support such as caring courses, carer support groups, dementia cafés, sitting services and services that can provide help in a crisis. Jack is told that his assessment will be regularly reviewed to reflect his own support needs.
	Jack meets with the Dementia Support Worker.	The Support Worker helps Jack with claiming a Carer's Allowance and tells him about the local Carer Support Group and the benefit of attending dementia cafes.
	Jack attends the local Carer's Support Group.	This gives Jack the chance to meet with people who have a similar caring role in a friendly environment where he can make new friends. Jack is told about letting his GP know about being a Carer.
Increasing Care (Including End of Life Care)	Jack visits his GP Practice to let them know that he is a Carer.	The GP will arrange for Jack to have regular Health Checks and advise him about how he can get help with other issues such as depression and anxiety.
	Eileen and Jack are supported through final issues.	Jack is given support by the Dementia Support Worker to enable Eileen to live in an environment that she would prefer and receive appropriate good quality care when needed.

# Section 3: Checklist

1) Understanding more about your diagnosis – for example, the type of dementia you have, what your drugs are for (if prescribed).

Should you require further medical explanations about your diagnosis, contact your GP or MAS assessor. The number for the Memory Assessment Service (MAS) is **0121 301 5440**.

Your MAS assessor will discuss therapies to support you following diagnosis as part of your support plan. If you choose not to take up the offer of therapies at the time of your diagnosis you can still make contact with the service later on to explore again. The MAS service is available on **0121 301 5440**.

Should you require help coming to terms with your diagnosis, please contact your local Dementia Adviser on **0121 706 4052**.

2) Talk to others about how you feel and ask your GP if there are any therapies or activities that could help you.

Your local Dementia Adviser will be able to sign post you to appropriate groups and support. Ring **0121 706 4052**.

Birmingham and Solihull Mental Health NHS Foundation Trust runs memory management groups and cognitive stimulation therapy. The number for this is **0121 301 5885**.

#### 3) Try some methods to help you cope with memory loss.

Your local Dementia Adviser can advise on assistive technology and how to manage memory problems. Ring **0121 706 4052**.

4) Introduce exercise to your daily routine and review your diet to make sure it is balanced.

Age UK Solihull now have local activity groups, their number is 0121 704 7846

Solihull Council run a Step into Solihull programme, their number is **0121 704 8207**.

Local church halls and community centres are also a good place to look for activities.

### 5) Organise regular check-ups.

Contact your GP, dentist, optician and chiropodist.

# Section 3: Checklist

#### 6) Arrange a benefits check for you and your carer.

Age UK Solihull will provide a benefit check, their number is 0121 709 7592

Your local Dementia Adviser can refer you to the Department of Work and Pensions (DWP). The contact number for the DWP is **0845 850 0293**.

#### 7) Write or update your will and appoint an attorney.

You can talk to your local Dementia Adviser about Power of Attorney. The Alzheimer's Society offer a free legal session, call **0121 706 4052** for further details.

Age UK also offer legal advice, call 0121 704 7840

8) Tell the DVLA/DVLNI and your car insurer about your diagnosis (if driving).

Contact the DVLA on 0300 790 6806.

9) Ask Solihull Council's Adult Social Care Team for a Community Care Assessment and a Carer's Assessment.

Solihull Carers Centre can help with the Carer's Assessment and can be contacted on **0121 788 1143**.

You can contact Solihull Council's Adult Social Care Team on 0121 704 8007.

# 10) Get in touch with the Alzheimer's Society to find out about local services for you and your carer.

The number for the Birmingham & Solihull office is 0121 706 4052.

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# Section 4: Services and Useful Contacts

Organisation	Contact Details	How they can help
Admiral Nurse Solihull	John Black Centre 4 Maple Leave Drive Marston Green Birmingham B37 7JB Tel: 0121 301 5878 Email: Jackie.Aird@bsmhft.nhs.uk	Support for carers Carers groups *REFERRAL VIA DEMENTIA ADVISER*
Age UK Solihull	The Core, First Floor, Solihull, B91 3RG Tel 0121 704 7840 info@ageuksolihull.org.uk www.ageuk.org/solihull	Advice for carers Care homes & agency lists Health Advice Managing your money including Benefits advice Bereavement advice Local trades people & avoiding scams Accommodation advice
Alzheimer's Society	Waterside House 7-9 Olton Wharf Richmond Road Solihull B92 7RN Tel: 0121 706 4052 Email: <u>BirminghamAnd</u> <u>Solihull@alzheimers.org.uk</u> Website: <u>alzheimers.org.uk/talkingpoint</u>	Advocacy Information & Advice Singing for the Brain Dementia Cafes Dementia Support Service Dementia Adviser Service Evening Carers Group Memory Cafe
Family Care Trust	6 Land Lane, Marston Green Birmingham B37 7DE Tel: 0121 770 1578 Email: <u>enquiries@familycaretrust.co.uk</u>	Day Centres Respite Care Community Support

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# Section 4: Services and Useful Contacts

Organisation	Contact Details	How they can help
Telecare (assistive technology)	Endeavour House Meriden Drive Kingshurst Birmingham B37 6BX Tel: 0121 717 1517 Email: info@solihullcommunityservice.org.uk	Includes telecare: alarms and alerts like falls detectors or exit alarms; stand alone technology like memory devices and trackers. Solihull Community Housing can provide a 24 hour responder service for those who don't have family members or other key holders.
Solihull Carers Centre	Solihull Fire Station Annex 620 Streetsbrook Road Solihull B91 1QY Tel: 0121 788 1143 Email: <u>centre@solihullcarers.org</u> www.solihullcarers.org	Carer advice and support
Solihull Handy Persons Service	Endeavour House Meriden Drive Kingshurst Birmingham B37 6BX Tel: 0121 717 1517 Email: info@solihullcommunityservice.org.uk	Affordable ways to repair, improve and adapt your home. Gardening service
Solihull Council Adult Social Care	Solihull Connect Contact Centre SMBC Offices, West Mall, Chelmsley Wood B37 5TN Tel: 0121 704 8007 Email: <u>ccadults@solihull.gov.uk</u>	Reablement Personal Budgets Home Care Day Care Occupational Therapy Assistive Technology/Telecare Wheelchair Service Disability Support Residential and nursing care Help Leaving Hospital

# Section 6: **Birmingham and Solihull Mental Health Foundation Trust Dementia Services:** Memory Assessment Service information

#### **Memory Assessment Service**

#### **Assessment and Diagnosis**

Following a comprehensive assessment and diagnostic process a person that has been given a diagnosis of dementia by the Memory Assessment Service, and their carer may be appropriate for early intervention services provided by Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT).

#### **Early Intervention Services**

The BSMHFT offers a range of early intervention services:

- Self-Management and Memory Group
- Caring in Dementia Group
- Cognitive Stimulation Therapy
- Dementia Medication
- Referral to Dementia Adviser Service (Alzheimer's Society)

#### Self-Management and Memory Group

This group provides support to people recently diagnosed and those involved in supporting them.

The group was devised following a evaluated research project undertaken by Coventry University and the BSMHFT following positive feedback on how effective the intervention was.

The group runs for 7 weeks and each session lasts for 2  $\frac{1}{2}$  hours.

#### **Caring in Dementia Group**

This group is for anyone caring for a person living with dementia. It is aimed at those new to the caring role and dementia.

The group runs for 8 weeks and each session lasts for 2  $\frac{1}{2}$  hours.



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#### **Cognitive Stimulation Therapy**

Recognition and

Identification

This group is for anyone in the moderate stages of dementia and is meant to actively stimulate and engage people, help maintain or improve memory and offer this in a socially supportive environment.

This service is only offered to the person living with dementia.

The group runs for 15 weeks (often on a twice weekly basis) and each session lasts for 2 hours.

#### Medication

Some people that have been diagnosed with dementia are suitable for medication to help with the symptoms. Medication is not effective for everyone and is only one element in providing support to those recently diagnosed.

Anyone considered as being suitable for medication will be seen by a doctor in an outpatient clinic and provided that they meet the criteria will be prescribed medication. This will then be followed up by a review session in clinic some weeks later to see if there are any side effect or if the medication is proving to be effective.

# See page 24 of the <u>Alzheimer's Society Dementia Guide</u> booklet for further information.

#### **Referral to Dementia Adviser Service**

A great deal of what is available to people diagnosed with dementia and their carers/family/friends is accessible via Alzheimer's Society.

BSMHFT has a partnership agreement with the Society through their Dementia Adviser Service and people recently diagnosed will be asked if they wish to be referred to this service.

The Society offers a range of services both to people living with dementia and their carers/family and the Dementia Adviser Service can make access to these services dependent on the needs of the person and their family.

To get more information about the above services please ring the Memory Assessment Service on 0121 301 5440.

Health Promotion

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Section 7: What people have told us about their experiences and some tips to make life easier.

Stories, experiences and comments from people with dementia and their families.



Recognition and Identification

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# At the reins

For Tony Fish, Wednesdays are the highlight of his week – a time when he can talk to his friends, take part in enjoyable activities and feel comfortable and in control. This is thanks to a Memory Café that meets every week in Solihull, where people in the early stages of dementia gather to meet with others in a similar situation.



Tony, 73, was diagnosed with Alzheimer's disease six years ago. Before his diagnosis Tony was a taxi driver who spent much of his day in the car. However, when his wife Margaret started to notice problems with both his memory and his driving he went to see a specialist doctor. From then on his life changed dramatically.

#### Lost independence

After having a brain scan and health check at a hospital in Birmingham it was confirmed that Tony had developed Alzheimer's disease. The diagnosis itself was a shock, but it was made worse when Tony was told he should no longer drive.

Tony explains 'The first thing that I was told by my specialist when I went to see him was that I should pack up driving. I was used to being independent and then suddenly it felt like I stopped being independent. Suddenly you have to rely on somebody else and that was the hardest part of me – giving up independence.'

'It does knock your confidence when you are diagnosed. One day you feel like you can do what you like and go here, there and everywhere. Then the next day you are told you can't do anything anymore and you have got to rely on someone else to do it for you.'

#### Welcoming group

A year after his diagnosis, however, Tony found some comfort when he joined the Memory Café in Solihull. From the outset he found the group, which was smaller than it is now, to be very warm and welcoming and full of people who were in the same position of having only recently been given a diagnosis of dementia.

Tony says 'I had a social worker and she told me about the Memory Café and asked if I would like to go to the group. She told me to go along, find out what it is like and if I don't like it I wouldn't have to go back again.'

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'I thought "let's give it a try" and I went along and everybody made me feel so welcome - it was only five or six of us then. After that we started doing activities and the group started to get bigger and we did more things. We started going to art galleries, ten-pin bowling, the police museum – we all found it very interesting.'

The Memory Café is not only about engaging in activities and going out on day trips. For Tony, the most crucial element has been the conversations with his peers. He says that the discussions are sometimes frank, but that everyone gets along and the fact that those who attend the group are all in the 'same boat' reduces feelings of isolation and stigma.

#### Fortunate ones

Five years since joining, Tony is an integral part of the Memory Café. As a long standing member of the group Tony helps to initiate conversations and makes newer members feel more comfortable, particularly if they have only recently been diagnosed with dementia.

The group is close-knit and Tony says that when he is with the group he feels 'normal' and that it is the rest of the world that is 'abnormal'. Attending the group and making friends has helped him accept his diagnosis and he feels that he is one of the 'fortunate ones' because he has such a strong peer support network to fall back on.

He adds 'There are an awful lot of people with dementia out there that don't have a group like this and I find that quite sad really. There are people who have still got a stigma about their own Alzheimer's disease and dementia – they want to hide it away and not be noticed.'

'Mostly our conversations at the Memory Café are about Alzheimer's disease and dementia and we discuss how people are doing and whether there is any new information or treatments on the market for people with dementia. If somebody is feeling down the other people try and pick them up and make them feel better,'

'At the group everybody tends to be like everybody else because we've accepted the fact that we've got dementia – it is about making the best of what you have got and you try not to let it get you down.'

'Other people might try to run you down but we don't run ourselves down in the group – the whole point is that you go every week, you have a laugh and forget the world outside and have a bit of fun for a few hours – it really makes the week worthwhile.'

Gerardine Sykes is the co-ordinator for the Solihull Memory Café and explains in more detail how the process works.

'We have planning meetings two to three times a year where we all sit down and discuss things that we have enjoyed, and things that we could include on future programmes. These meetings are always very useful and there is usually lots of input, with suggestions for speakers and activities – I then do my best to put everyone's ideas into practice.'

'For me it is very important that everyone has their say. With a largish group that currently has 16 members it is obviously not possible to please all of the people all of the time, but through having input from all the members we can try to make sure that the speakers and activities are meeting the needs of most people. Over a period of time we have had a wide variety of speakers, activities and outings.

#### 'Hands off' approach

Those who have been invited to talk at the Memory Café include the local police and fire service and Guide Dogs UK. Activities chosen by the members have included yoga, poetry composition, painting, handbell ringing and dance and exercise sessions.

For the Memory Café the staff also make sure to take a 'hands-off' approach to running the group – allowing those who attend to get on with the agenda for the day and only stepping in when needed.

However this approach is aided by good planning. Before the sessions begin Gerardine and her team make sure to set up the room in a way that encourages conversation and positive relationships in the group – for example, by sitting good friends next to each other. She says that the positive effects of these peer support groups on dementia are abundantly clear.

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For Tony one of the reasons the Memory Café is successful and well loved by

Diagnosis

Planning meetings between staff and members are held several times a year and it is here that the people with dementia have their say on the speakers they would like to invite to the group and the activities they would like to engage in. The support team then endeavours to meet their requirements.

those who attend is that the Alzheimer's Society staff who run the weekly group leave the people with dementia firmly in control of the reins.

She adds, 'As this is a peer support service and we are not members of that peer group it is important that we are there to facilitate, encourage, nurture and enable people to socialise and get to know each other and trust each other – it is through this that we see the peer support. However, although we are "hands off" we are very aware of the wellbeing of each member of the group and will be involved when needed.

'Everyone is encouraged to be as independent as possible. Most members make their own tea or coffee when they arrive and sometimes one of the members will propose a vote of thanks to a speaker.'

'Members do certainly gain confidence within the group – and they tell me that this helps with confidence in other situations. Carers have also said that the Memory Café has helped with confidence.'

#### Looking after each other

The confidence and comfort that the Memory Café members feel within their peer group is illustrated by the fact that they originally approached Living with dementia magazine with a suggestion for an article.

Gerardine says that the group also make sure to look after each other and she points to how Tony has supported fellow members of the group as an example of this.

'When we had to move premises last year one of the members who lives alone wouldn't have been able to get to the meetings but Tony and his wife very kindly offered to bring him and take him home. This is typical of Tony acting very much as a team player and having the welfare of the rest of the group at heart.' She adds.

#### QUICK READ

# Tony Fish was diagnosed with dementia six years ago after his wife noticed problems with his memory and his driving. He has benefitted a local peer support group.

Tony found the loss of independence that followed the diagnosis difficult. A year after diagnosis he was referred to a weekly Memory Café in Solihull, for people in the early stages of dementia.

Five years after Tony started attending the Memory Café he has come to accept his diagnosis through interacting with others in the 'same boat'.

The Memory Café is led by people with dementia. They set the agenda – deciding on topics, guest speakers, activities and outings. Alzheimer's Society staff support and help the members where needed.

# Story about Singing for the Brain

Three members of the same family came for the first time to one of the Singing for the Brain sessions hosted in one of our two Solihull venues. A granddaughter, mother and grandmother all came to experience a session together.

Grandmother – Mary

Mother - Ruth

Granddaughter - Lydia

Ruth explained to me prior to the start of the session that her mother Mary sometimes displays restlessness and agitation and as a carer it caused her to feel despondent to be unable to find an activity which can create calm and happiness for her mother. Ruth and Lydia had spent many months looking for services and interventions which Mary could take part in, but nothing had been effective.

All three members of the family came along to the Singing for the Brain session and sat together in the circle of 25 others. The family were nervous but excited to be part of a friendly group and ready for a new adventure.

The first few songs began with the leader settling the group and ensuring we were familiar with one another. Then by about 20 minutes into the session, Mary was clearly humming, tapping her feet and smiling at all the others in the circle.

Ruth and Lydia were very emotional to see how much engagement Mary was able to display during the hour session.

I spoke to Ruth at the end and she said how much reassurance she felt from finding an activity which she felt her mother could experience in her own right as a person with dementia

Ruth said;

'I can't underestimate the value of this service, I will definitely be coming back with mum and it makes me happy that 3 generations of my own family can share this. I have gleaned a little bit of my mum today who I thought I had lost, but she is still with us and watching her sing and move to the music-what a wonderful morning!"

Names in this case study have been changed.

## Example of the type of support from a Dementia Adviser

A lady in Castle Bromwich who has been caring for her husband since May 2013 met with the Dementia Adviser. During this first meeting a number of actions were identified including: -

- Mind Stimulation and Social Engagement the carer's husband spends most of the time sitting in a chair at home and falling asleep
- Application for Council Tax reduction the carer's husband was in receipt of the lowest rate of Attendance Allowance and was not aware that a 25% reduction in Council Tax may be available
- Dealing with challenging behaviour the carer was finding it difficult to help her husband get undressed and showered in the morning

A provision to provide carers seven days a week in the evening had already been put in place to help the carer's husband get undressed and ready for bed. This provision is self-funded and so any reduction in Council Tax will help the carer to contribute to this and any other support needs that may be identified.

To progress the above actions the Dementia Adviser/ Dementia Support Worker -

- Made a referral to AGE UK for a benefits assessment. Specific reference was
  made for the need to assist the carer to complete the reduction in council tax
  form and also to investigate whether the higher rate of Attendance Allowance
  can be applied for given the difficulties that the carer was now experiencing
  getting her husband up and ready in the morning.
- Requested the application form for the reduction in council tax from Solihull Council
- Discussed ways of dealing with challenging behaviour and sent out relevant fact sheets to the carer by post
- Discussed ideas for activities in the home including an activity box with memorabilia of motor bikes. During a conversation with the carer's husband the worker discovered that he had an interest in motor bikes

Later, the worker took another call from the carer outlining that the situation in the morning with changing clothes and bathing was not getting any better and that signs of agitation were being displayed with a refusal to take medication.



Another home visit was arranged during which the following actions were agreed with the carer and her husband: -

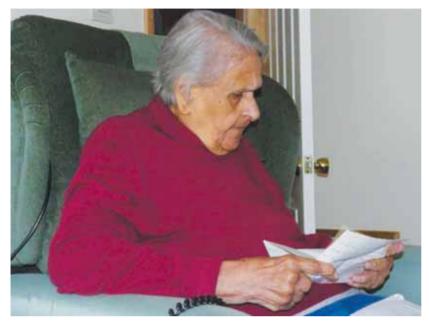
- A referral to the <u>Admiral Nurse</u> for the provision of appropriate support to help get her husband up and ready in the morning and also coping strategies for dealing with stress and anxiety.
- A telephone call to Solihull Council's Adult Social Care Team 0121 704 8007 (to request a carer's assessment and to look at additional carer support in the mornings and a place in a day centre - the husband was still not engaging in any type of activity. The worker did talk to the husband about a place in a day centre and he agreed to consider this option.

In addition, the worker suggested that the carer contact the family GP to discuss the issues around the husband taking medication and agitation, in particular to find out if alternative types of medication are available and for a health check to rule out infections etc. as a possible cause of the agitation.

In summary, the above demonstrates swift identification of needs with appropriate actions and interventions to support both the carer and person with dementia, specifically putting in place strategies to deal with her husband's behaviour in the morning, especially the agitation and alleviating stress. The carer was concerned that although the signs of agitation were limited to shouting they may lead to other things. Signposting / working with strategic partners is also evident.

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# Going into respite



When you make the decision to place the person you are caring for into respite whilst you take a well earned break it can be difficult emotionally. Jean struggled with this when making the decision to book he mother into respite care but then she had a great idea...

"The first time mum spent in respite was quite strange for her as it was something that had never happened before in her life –being away from her family. So, the subsequent times she was away I thought of a way of keeping 'in touch' and her knowing that she was thought about. I did this through writing letters to her in advance of us going away so that she had something from us while she was there.

In the letters I talked about things that we were going to do, for instance somewhere that she had visited previously with us and asked if she had remembered. I anticipated what we might be doing etc, telling her not to miss the royal wedding as she will have to tell me what she thought of it all. I also sent a post card which had a photo of a shop directly across the road from the shop we bought it from so I was able to tell her that. The last note was about packing up and coming home in a days time when we would come and collect her. Also anything thing else I could think of. I kept them relatively short."

This is a lovely example of something very simple that brought peace of mind to both Jean and her mother.

# Quotes for Solihull Information project (feedback from people who have used services).

- I appreciate the interest that xxxx showed in my condition, this so helped me feel less of an outsider.
- Most helpful when I phoned the office, the information arrived the next day and then a very supportive home visit."
- I felt very relieved when I spoke to xxxx, he seemed to understand my feelings of frustration and isolation, and now I know he is only a phone call away if I need more support.

I finally found someone who could actually really help me to plan for the future, I have now put in place all the legal bit and pieces, so I can relax about that and get on with living and coping.

- I feel like I understand the symptoms better now, I can sort of understand why my husband behaves like he does, xxxx explained this to me and I also read the information she left for me. I am a little more content to know she is just at the end of the phone if I need her, I do worry about what might be next.<sup>33</sup>
- I have never even heard of a dementia café, when xxxx suggested I go along I wasn't keen, but I am so pleased that I did, now I have some new friends who also have something in common with me and my husband.
- I look back now and realise how much I was refusing to listen to the dementia adviser; she tried to make me see I couldn't understand my husband's changing moods and behaviour. I can see it all now so much more clearly .I called her back because I don't know where to turn now, and I am pleased I have her and I can sound off when things get too hard for me. <sup>17</sup>

# Section 8: Living well with dementia

# Five simple ways to help someone with dementia

- 1. Respect and dignity focus on what the person can do, not what they can't.
- 2. Be a good listener and be friendly support and accept the person, be patient.
- **3.** Do one little thing cook a meal or run an errand, it all helps.
- **4.** Make time for everyone partners, children and grandchildren will be affected. Could you do something to help one of them?
- 5. Find out more understanding dementia makes living with it easier.

# **Practical Tips**

- Encourage them to keep a notebook or diary for things such as appointments, to do lists, thoughts and ideas.
- Keep important things like money, glasses, and keys in the same place.
- Put labels on doors and cupboards.
- Place important numbers by the phone where they can be seen easily.
- Put a note on the back of the door as a reminder to take keys.
- Label family photographs, both on display and in albums.
- Pin a weekly timetable to the wall.
- Mark a calendar with the date or get an electronic calendar that changes automatically.
- Write reminders to lock the door at night, turn off the gas off and put rubbish out on a certain day.

Assessment and Diagnosis Living Well with Dementia Increasing Care (Including End of Life Care)

There are products you can buy which are designed to help with memory problems – telephones where the buttons are replaced with photos of people, and pill boxes with compartments for different days. An occupational therapist may be able to advise you on what things could be most helpful (you can find out about an occupational therapist through your GP or Solihull Council's Adult Social Care Team).

# Showing that you understand

A diagnosis of dementia can cause different emotions, many of them difficult to manage both for the person with the illness and those around them. There may be a sense of relief now that they know what the problem is so that they can begin to deal with it.

A person with dementia will probably be sad or upset at times. In the earlier stages, they may want to talk about their anxieties and the problems that they are experiencing. Try to understand how they feel, and don't brush their worries aside, and show that you are there for them.

# When someone has dementia they need:

- Reassurance that they are still valued, and that their feelings matter.
- Freedom from as much external stress as possible.
- Appropriate activities and stimulation to help them to remain alert and motivated for as long as possible.

Many people who have dementia develop what appears to be unusual or inappropriate behaviour. Remember their actions may be perfectly rational to them. You may need to think about how their altered view of the world may lead to different ways of thinking and behaving.

A person with dementia is not being deliberately difficult. Often their behaviour is an attempt to communicate. If you can establish what this is, you can resolve their concerns more quickly. Try to put yourself in their place and understand what they are trying to express and how they might be feeling.



This is a specialist befriending service which enables older people to receive social and practical support at home, and also enables isolated people to interact with others either at home or in their local community.

# **Carers' Support Scheme**

We offer a sitting service that provides respite to carers of people fifty years and over suffering from conditions that cause confusion or dementia.



# **Putting Safety First**

# Ways to Prevent Falls

# Putting Safety First Ways to Prevent Falls

- The risk of falling is a common problem which can often be avoided by following a few safety tips.
- Experts in their field have contributed to this booklet so that the best and most up-to-date information is available for you.
- This booklet contains advice on what to do if you, or someone else falls.
- Keep this booklet handy so that you can be reminded of the advice.

Inside this pack you will find information on:				
General Safety	p2-7			
Medicines	р8			
Postural hypotension/dizziness	р9			
Vision and Hearing Loss	p10			
• Exercise	pll			
Footwear & Footcare	p12			
Hydration	pl3			
Osteoporosis	pl4			
◆ Diet	p15-17			
What to do after a fall	p18-19			
Contacts	p20			

The important thing is that preventing falls is not just about hazards around you, but it is also about what you wear on your feet, what you eat, how active you are and what steps you take to prevent falls happening.

For more help and addresses see **Your Local Contacts** on the back page of this booklet.

# Help Yourself to Health loss of confidence

If you have had a fall or are worried about falling there are some important things to remember:

- Anyone can have a fall you are not alone!
- Falling is frightening and people do feel less confident after a fall. Do you find that you:
  - I. Are more careful with your walking, maybe slower or doing less?
  - 2. Are leaving the house less often, or not going as far?
  - 3. Are worried about what might happen if you fall again?
- Answering yes to one or all of these questions is common and may mean you have lost some confidence.
- But remember there are lots of things that you can do to reduce your risk of falling and improve your confidence.
- This booklet is full of ideas to help increase your confidence by taking control. Keep reading to learn what you can do to help yourself.
- If your concerns are affecting you a lot then speak to a member of the health care team.

# Hints and tips to reduce the risk of falling. In your BATHROOM...



**DON'T:**Lock the bathroom door

Have the water too hot

# In your **BEDROOM**

# DO:

- Make sure your bed is the right height for you and your mattress offers comfort and support..
- Have a light by the bed that can be switched on and off easily from the bed.
- Have a torch with good batteries by the bed in case of an emergency or power cut.
- Have a telephone extension or charged mobile phone by your bed in case of emergencies.

If you are part of a warden or home call service, remember to have your alarm call pendant, panic button or pull cord in easy reach.

# DO:

- Try to have someone in the house when you take a bath or shower. If this is not possible you could let someone know how long you think you will be. If they do not hear from you after an agreed time they can then check you are OK.
- Use a non-slip bath mat.
- Make sure you have everything you need, e.g. shampoos, soap, towels before you get into the water.

You may be eligible for help with the cost, use or fitting of support aids - find out which bathroom equipment can be fitted for you, such as grab rails or seats.



# In the HALL and on the STAIRWAY...

#### DO:

- Make sure halls and stairways are well lit with light switches on both levels.
- Keep stairs and walkways clear from obstructions and, if possible, fit stairs with two handrails.
- Do fit a cage or box to the inside of your Letterbox if possible to save you bending down.

# **DON'T:**

 Leave belongings and obstacles in your hallway or stairway that you could trip over

# In the KITCHEN...

#### DO:

- Make sure work surfaces are clear and within easy reach in case you need to put hot or heavy items down quickly.
- Keep everyday items in easy reach avoid storing things in high or low places.
- Use steps with handle grips for support If you do need to reach high cupboards. Do not balance on a stool or chair.
- Wipe up spills immediately, slippery floors can cause a fall.

# **DON'T:**

- Reach up to high cupboards.
- Store everyday items too high or too low.
  - Not balance on a stool or chair.

# HEATING

 If you have a gas fire try to have the controls and ignition switch fitted on top of your fire. A qualified gas engineer will be able to advise you if this is possible. Your utility company may also be able to offer free advice.

# Answering the DOOR or TELEPHONE...

# DO:

- Take your time if the call is important they will wait. You can call out to let them know you have heard their knock/ the doorbell.
- Have an intercom fitted so you can talk to the caller before going to the door.
- Use an answer phone to take your calls you can still speak to the caller when you reach the telephone.
- Use a portable phone (keep it fully charged) remember it may not work during a power cut.



 Be tempted to hurry to the door or telephone.

# Wear the right CLOTHING...

#### DO:

• Wear clothing that allows your legs and feet to move freely.

# DON'T:

 Wear clothing that is too long or too tight.

# Is your FURNITURE safe?..



# DO:

- Arrange furniture so that it is stable and can't topple over.
- Remove casters from chairs to make them stable.
- Make sure you can move freely around the room - furniture should not be used as a walking aid.

# DON'T:

- Lean on furniture which could move or topple over.
- Use furniture as a walking aid.

# Good LIGHTING helps avoid falls...

#### DO:

- Keep rooms and stairways well lit.
- Use the brightest bulb available to you, to make it easier to see.
- Use long life bulbs they can be left on longer and use less electricity. If you
  do not feel confident replacing a bulb ask for help, do no put yourself at risk.
- Long life bulbs may take a minute or so before they reach their full brightness.

# **CARPETS** and **RUGS**...

#### DO:

 Make sure carpets and rugs are tacked down or removed if it makes the room safer.

# WALKING AIDS...



#### DO:

- Make sure you use walking aids that are provided for you.
- Check the rubber at the base of your walking aid and change when worn down.

## **DON'T:**

 Attempt to carry objects when using a walking frame - some aids are fitted with a carrying bag for small items.

# WIRES and REMOTE CONTROLS...

# DO:

 Make sure all electric wires, telephone, television and computer cables are tucked away so you don't trip over them.

# Safe use of MEDICINES...

Some medicines can make you more likely to fall for example: antidepressants, sleeping tablets and other sedatives. Sometimes tablets for blood pressure can work a little too well and make you dizzy when you stand up.

#### **NOTE:**

 It is important you do not stop taking a medicine without first asking your doctor

# DO:

- Follow the instructions for taking your medicines.
- Check medicines are working and not causing you problems regularly review you medication with your Doctor or Pharmacist (chemist).
- Ask your surgery about a medication review if you or someone you care for is struggling to take medicines as prescribed.
- Ask your surgery for a medication review if your treatment has changed recently and you are unsure about your medicines.
- Talk to your community Pharmacist (chemist) if you have difficulty opening child-resistant tops. They may be able to give you ordinary screw tops or different packaging.
- Be aware of feelings of dizziness or excessive drowsiness and speak to your doctor if you are concerned.
- Know your medicines all medicines are supplied with patient information leaflets and provide details about possible side effects.

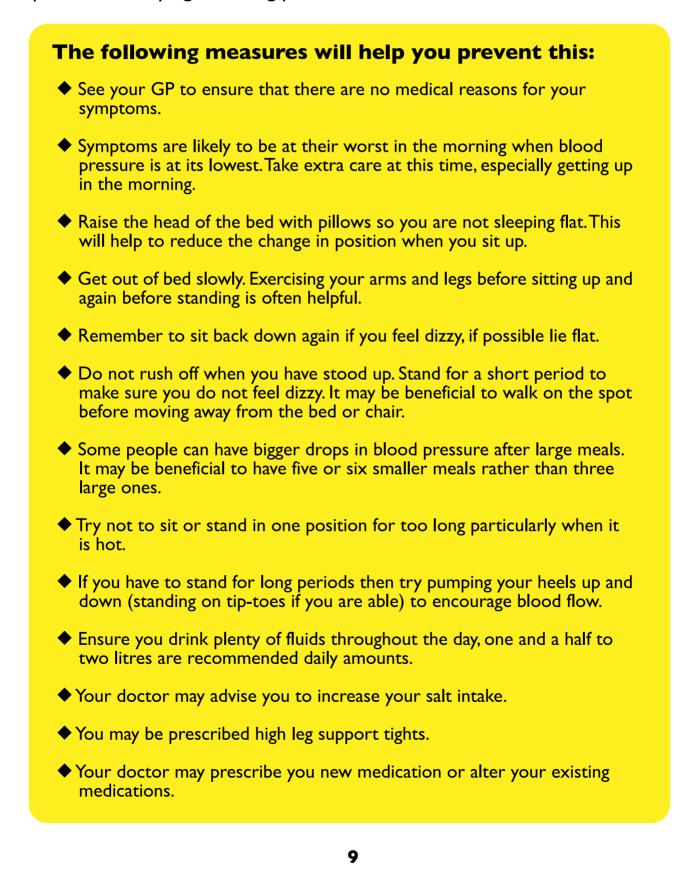
# **DON'T:**

- Change the amount you have been told to take or take it at a different time without first discussing it with your Doctor or Pharmacist (chemist).
- Share or give your medicines to anyone else. They were prescribed for you and may be harmful to other people.

# **Postural Hypotension/Dizziness...**

Postural hypotension is a drop in blood pressure during a change in position. This reduces the amount of blood going to your brain and can cause symptoms of dizziness, falls and blackouts.

The fall in blood pressure can occur at any time and may happen after getting up from either lying or sitting positions.



# **VISION** and **HEARING** loss...

You can experience falls due to sight or hearing loss

# VISION

# DO:

- Have your eyesight checked regularly If you are aged 60 or over your eyesight tests should be free. You may also qualify for help towards the cost of your glasses.
- Remember to wear your glasses and keep them clean and in good condition.
- Contact your optician to ask if they can visit you if you are housebound.
- Take care on steps and stairs when you wear your glasses especially if you wear varifocals or bifocals.

If you are registered blind or partially sighted there is a range of support available from your NHS eye department, social services and a range of dedicated charities.

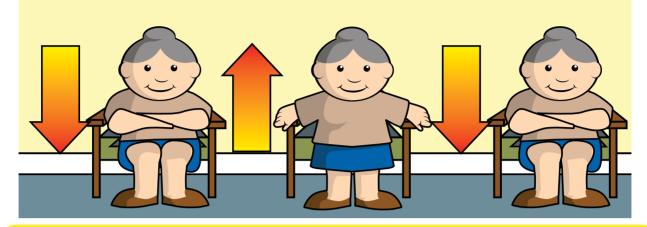


# **HEARING** loss...

# DO:

- See your Doctor if you have difficulty with hearing who can refer you to hospital for checks.
- Make sure you attend your regular appointments with audiology if you already wear a hearing aid.
- Maintain your hearing aid, keep it clean and replace batteries regularly.

# Lead an active lifestyle Stay fit for life



#### DO:

- Regular exercise and movement can prevent the risk of falling.
- Regular physical activity, such as walking, helps to strengthen muscles and bones.
- Follow the recommended level of exercise, depending on your general health.
- Always check with you Doctor or Nurse before starting a new type of physical activity or returning to exercise after a break. They can also help provide advice on diet and nutrition.
- Build up to walks that last half an hour at least four times a week, ideally a short walk everyday is your goal. Walking regularly can be just as beneficial as bursts of strenuous activity.
- Remember to warm up and cool down with some gentle stretching.
- Wear loose fitting clothing and suitable footwear. Sticks can be a useful aid for balance, some even fold out into a seat.
- Try and plan a route that has things to see and benches at vantage points for rests, if you need them.
- Tell someone where you are going and when to expect you back.
- Ask your Doctor or Nurse if they have 'GP Referral Scheme'. Often the provision is available at a reduced cost or free. Some Doctors prescribe exercise at participating gyms.
- Check with your local gym or class provider for information about exercise classes. There are a growing range of types suitable for all ages and abilities such as aerobics, pilates, gentle exercise.

Regular arm and leg movements can be achieved while sitting in a chair. Swimming pools also provide sessions and are able to support individuals with limited mobility.

# DON'T:

- Exercise if you are tired, ill or just after eating. Try not to overdo it, build things gradually.
- Make sudden or jerky movements such as tipping or turning your head. Standing up quickly can cause dizziness.

**FOOTWEAR** and **FOOTCARE** 

As we get older our feet often start to protest about the way we have treated them over the years - so it's important to take good care of them.

The following will help you to care for your feet and may help to reduce the risk of falling.

# **FOOTWEAR DO:**

- Take care of our feet and choose the right footwear for support.
- Ask to have your feet measured when buying new footwear. Shoes, boots and slippers should fit properly. The size and shape of our feet can alter throughout our life.
- Choose footwear that protects and supports with non-slip soles, this will reduce the risk of slipping on some surfaces.
- It is important you feel safe and secure when you walk. Fastenings such as laces, buckles and velcro help to secure your feet inside your footwear.
- Ensure natural foot movement when you walk, shoes with soft uppers, high sides and an enclosed heel help to provide this. Avoid footwear we thick spongy soles.

#### Good simple footcare is important

# **FOOTCARE DO:**

- Wash your feet daily in warm soapy water, rinse and dry with a soft towel taking care to dry between your toes.
- Use a foot file to remove dry, hard skin and rub moisturising cream into the soles and heels of your feet.
- Trim your toe nails at least once a month. Always cut them straight across without cutting down the sides of the nail.

There are a range a inexpensive foot care products available through your local Chemist. If you need advice speak to your Doctor, Nurse, Registered Chiropodist or Podiatrist.

# DON'T:

 Ignore minor foot troubles. They are unlikely to get better by themselves. If you are in any doubt, see your Doctor or see a State Registered Chiropodist or Podiatrist especially if you have diabetes mellitus.

# **STAYING HYDRATED**

## How are you feeling?

Do you suffer from headaches, dizziness, confusion or tiredness. You may need to drink more water and discuss these symptoms with a Health Professional.

#### Is your urine clear?

Check against these colours.



illness, falls and infection. Checking the colour of your urine is one way of telling if you are drinking enough. Dark, strong smelling urine maybe an indication your body is dehydrated or you have an urine infection. If in doubt get it checked out.

# Ideally it should be a pale straw colour – the clearer the better.

For our bodies to function well we need to drink regularly throughout the day. Some drinks are more effective hydrators - water is excellent.

# As a general guide:

- Aim to drink between 1.5 and 2.5 litres (2.5 4 pints) of fluid a day, unless otherwise advised by a Health Professional
- Roughly 6 8 glasses (x 250ml). Can be taken in a variety of hot and cold drinks (limit alcohol) and keep the balance right. Aim for at least 4 glasses of water a day
- Keep caffeinated drinks to a minimum
- Try changing to caffeine free tea or coffee
- ◆ Tap water is an ideal choice. It is free and contains no sugars or calories
- Milk, fruit juice and squash are good alternatives to water
- Being dehydrated affects blood pressure and can increase your risks of falls

# **OSTEOPOROSIS...**

Osteoporosis is a common condition where bones have become very fragile and weak making them easy to break. There are many factors that may increase your risk of osteoporosis, such as.

- A broken bone after a minor bump or fall
- A family history of a broken hip after a minor bump or fall
- Undergoing the menopause before the age of 45
- Taking corticosteroid tablets (cortisone, prednisolone) for more than 6 months
- A loss of height of more than 5 cm
- Irregular periods (stopped for 12 months or more for reasons other than pregnancy or the menopause)
- Drinking heavily
- Frequently suffering from diarrhoea (caused by problems such as Coeliac disease or Crohn's disease)

#### Suffering from certain medical conditions such as:

- Rheumatoid arthritis
- Malabsorption syndrome
- Chronic kidney disease
- Liver disease
- Low testosterone levels in men

Having one or more of these factors may make you at risk of osteoporosis. Your Doctor or Practice Nurse can advise regarding further tests or treatment if necessary, consult them if you are concerned. If diagnosed with osteoporosis treatments are available to help strengthen bones.

#### To protect your bones...

# DO:

- Stop smoking as this can damage the bone building cells in the body.
- Keep your alcohol intake low. Excessive alcohol can destroy bones and make you unsteady.
- Try to take some sort of exercise see our section on 'Get Moving'.
- Try to go outdoors often, as daylight is an important source of vitamin D, essential for strong bones.
- Eat a well balanced diet see 'What I eat' section

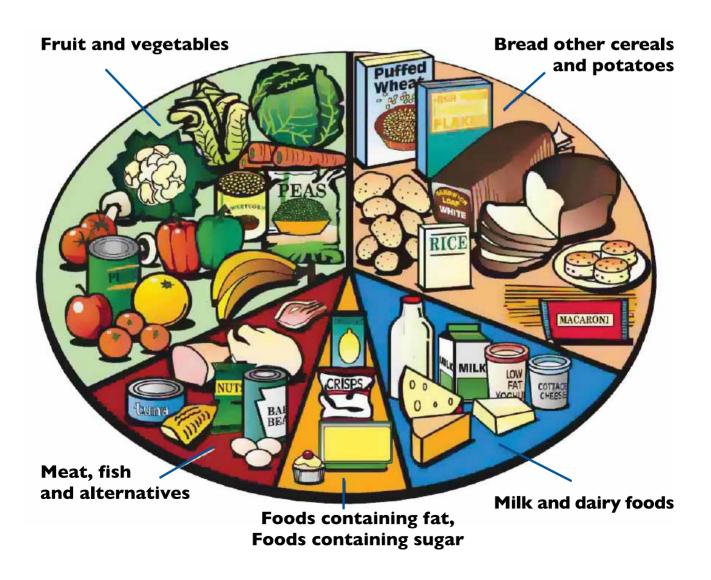
# Does your diet make a difference?

YES! - what you eat makes a difference, it is important to eat a wellbalance diet to take in all the protein, vitamins, minerals and other nutrients your body requires.

Eating a well-balanced diet helps to keep bones and muscles healthy and in good working order. Having strong bones helps to prevent falls.

The diagram below shows the proportions of food you should eat to achieve a healthy, balanced diet.

Your weekly meal plan should use some of the foods below to give a varied, interesting and portion controlled diet. It may be beneficial to have five or six smaller meals rather than three large ones.



# **CALCIUM** and **VITAMIN** D are particularly important nutrients...

# 

A good supply of calcium is essential for the development of strong, healthy bones and for the prevention of soft/brittle bones (known as osteoporosis) in later life.

Milk and dairy foods are the richest sources of calcium. These include:

- ♦ Milk
- Cheese
- Yoghurts
- Fromage frais
- Milky puddings

Other sources of calcium include:

- Fish with soft bones (sardines, salmon and pilchards)
- Dried fruits (apricots, prunes, raisins and dates)
- Dark leafy green vegetables
- Kidney beans and lentils
- Bread, especially white bread
- Nuts

Vitamin D is needed by your body to absorb the calcium from your diet. The main source of vitamin D comes from the action of sunlight on your skin, so try to spend some time in the sunlight every day. If this is not possible, vitamin D can also be obtained from certain foods.

#### Food sources of vitamin D include:

- ♦ Margarine
- Eggs
- Liver
- Oily fish (pilchards, mackerel, salmon and sardines)
- Breakfast cereals.



# What should I do if **have a fall?**

# What to do:

- Be prepared knowing what to do could be life saving.
- Try to Keep calm, if you have a panic button call for help even if you think you are OK.
- Check to see if you are near a telephone to call for help. If in doubt call the emergency services. If your phone has 'speed dial' buttons have them programmed so you do not have to remember phone numbers if you are in pain or shock.
- If your neighbours may hear try calling for help. You may want to place a key with them for safe keeping in case of emergencies.
- Check to see if you are injured. There are first aid booklets available to help you
  prepare for minor injuries.
- Check the area for any items you may have dropped and broken. You do not want to cause further injury by moving.
- You may want to try getting up from the floor. Think about how you can do this in stages, moving so you are nearer a chair or settee first. Then get on your hands and knees before getting up.
- Try and keep warm, see if there is a blanket, coat or towel nearby that you can use.



# What should I do if somebody else has a fall?

## What to do:

- Be prepared knowing what to do could be life saving.
  - S Stop
  - **T** Give yourself **T**ime to think
  - **O O**bserve the situation
  - **P P**rotect yourself, do not put yourself in danger
- Try to Keep calm
- **Check for danger** are there signs of any liquids or broken items such as glass or crockery. Do not put yourself in danger.
- Check the casualty for a response.
   Q:Are they Alert and aware of visuals or vocal sounds?
   Q:Are there any obvious signs that they are in pain?
   Q: Can they tell you what happened?
   Q:Are they unresponsive i.e. asleep or unconscious?
- Call for help Dial 999, Sound the panic button if the casualty is part of a warden scheme or call for a neighbour.
- Follow the advice given by the emergency services to check and make the casualty comfortable.
- Keep the casualty calm, warm and reassured until help arrives.

# **DON'T:**

- Give them anything to eat or drink.
- Put yourself at risk call for help.

# And Finally.....

When the weather is cold you can easily suffer from hypothermia if the temperature of our home is not maintained. Falls that occur during cold weather, particularly if you are lying on the ground for even a short period of time, can result in serious consequences.

#### Tips for keeping warm

- Ensure your home is heated to no lower than 21°C
- Keep internal doors closed to stop draughts
- Have at least one hot meal per day and have plenty of hot drinks
- Layer up many layers of clothing are best
- Use a regularly serviced electric blanket or heat pad
- Close curtains at dusk
- Keep your heating on overnight and close windows
- Contact your energy supplier and find out about Social Tariffs or Priority Register Schemes
- Ensure your home is well insulated & your boiler is serviced regularly

# Help Yourself to Health..... PREVENT FALLS Your local contacts

### Winter Warmth Line 0121 704 8080

Help people keep warm by providing advice, tips and can offer practical help and support to make your home more energy efficient

## Age UK Solihull 0121 705 9128 or ageuk.org.uk

Provide help and advice to local older people

# **Community Services**

Contact your GP to access the following:

- District Nurses
- Rehabilitation at home
- Chiropody service
- Advice about diet & weight management
- Advice on giving up smoking
- Specialist Nurses who can help you cope with long term diseases such as; Diabetes or respiratory and heart diseases

# Adult Social Care services provided by Solihull Council 0121 704 8007

Solihull CONNECT provides information and advice about council services either in person at the walk in centres, or by telephone email or fax.

You can also get information and advice about services provided by partner organisations

# Solihull Osteoporosis Support Group -0121 705 8385

(Correct as of Feb 2012)

Provide support to people affected with Osteoporosis; regular exercise classes, meetings throughout the year and fundraising events. Useful information relating to Osteoporosis can be obtained from the National website **nos.org.uk** 

# ...Other Useful websites

arthritiscare.org.uk parkinsons.org.uk smokefree.nhs.uk

# For further information please contact

# COMMUNITY FALLS ADVISOR 0121 712 7272

Who can provides advice and information on falls prevention and keeping active in later life