

NHS Gloucestershire Gloucestershire Hospital NHS Foundation Trust <sup>2</sup>gether NHS Foundation Trust Gloucestershire Care Services NHS Trust

# Living Well Handbook







# Living Well Handbook

# Welcome to your Living Well Handbook

The Living Well Handbook was inspired by people living with dementia who wanted one place to store essential information; similiar to a passport.

# The handbook holds:

- Information that you feel is important to share.
- Information that is helpful to you now and in the future.
- Information that ensures your care is based on your needs.

# **Using your Living Well Handbook**

The first sections of the handbook are for you to complete. It is a good idea to do this with someone who knows you well. So that you can record the key things you want others to know about you.

# **Section 1 – Emergency Details**

This holds essential details that might be needed by the emergency services, or people who might be stepping in to support you at short notice.

# Section 2 - About Me

This part of the handbook builds up a picture of you and the things that are important to you. Professionals can use the Living Well Handbook to plan care that meets your needs.

Through out this handbook, sections have been designed to lift out. This allows you to share shorter versions of the information without losing your folder. For example, if you go into hospital.

# **Section 3 – Care Planning Information**

You can record the name and contact details of anybody involved in your care and the way you are best supported (care plans). This helps you to contact people and also to share information between services caring for you. This section also contains a page where your current prescription details are recorded, it is important for these to be up to date as possible.

# **Planning for Your Future Care: Advanced Care Planning**

Helps you to plan for the future; you can share your wishes and preferences with those close to you or who may care for you.

# Alzheimer's Society - This is Me leaflet

Is invaluable if you need to go into hospital or a care home, and is a shorter revision of your handbook that can be replaced.

# **DisDAT Pain Assessment Tool**

Tells people providing your care how you might be affected by pain or distress. It is particularly useful for doctors and nurses caring for you in hospital who do not know you as well as your GP.

# **Personal Events and Calendar**

Records important dates, appointments and information.

# Section 4 - Getting information about dementia

This section lists the main organisations that can give you information and support to understand your diagnosis, plan for the future and get the help you need.

# **Section 5 – Useful contacts**

Lists local and national organisations offering services, support and information.

# Introduction

My name is \_\_\_\_\_ and this book is about me.



All of the information that I and anyone else needs to help me live well with dementia will be in this handbook, so please help me to keep this information up to date.

Thank you.

Contents		
Section 1	Emergency Details	
Section 2 Section 3	About Me Care Planning Information Personal Events and Calendar	
Section 4 Section 5	Getting Information About Dementia Useful Contacts	

# **Section 1**

# **The Carers Emergency Scheme**

# **Registration Number:**

Contact Adult Social Care Helpdesk (01452 426 868) if not yet registered.

# **Emergency Details**

Name	
Date of Birth	
Address	
	Post code:
Telephone Number	
GP Name	
Address	

# More details can be found in Section 2

# **Carer Contact Details**

Main Family Carer	Second Contact
Name	Name & Relationship
Address	Address
Mobile Number	Mobile Number
Home Number	Home Number
Work Number	Work Number

Key Holder	Neighbour
Name	Name
Address	Address
Mobile Number	Mobile Number
Home Number	Home Number

# **Medical Details**

Medical history		Date
Allergies	See page 16 for curr	ent medication
		Date
I may use the following:		
Hearing Aid	Dentures	
Glasses	Walking aid	
I agree that the personal information contained in this <b>Living Well Handbook</b> can be shared with Health and Social Care professionals.  Signed:		

For information about how dementia affects me, please refer to Section 2

The "This is Me" information supporting hospital admission can be found in Section 2

# **Section 2**

# Part 1 Supporting Me

PLACE YOUR PICTURE HERE

PLACE YOUR PICTURE HERE

My name is:

I like to be called:

My belief or faith is:

The people who are important to me are:

The people who usually look after me and know my needs best are:

# **Talking to Me**

My first language is:			
I wear glasses for:			
My last eye test was:			
I use a hearing aid in my: left ear / right ear / both ears			
The batteries are :			
My last hearing test was:			
Eating and Drin	ıkina		
Tlike:	ikirig	I don't like:	
The hole I would to get in		The hale I was also divisit in	
The help I need to eat is:		The help I need to drink is:	
I wear dentures:			
Moving About			
The help that I need is:			
I use a walking aid:			
Hygiene			
I prefer to:			
Strip Wash Every day	Shower Every 2/3 days	Bath Every week	
I need help with:	Lvcry 2,0 days	Every Week	
When at home I like to wear:			

# **At Night**

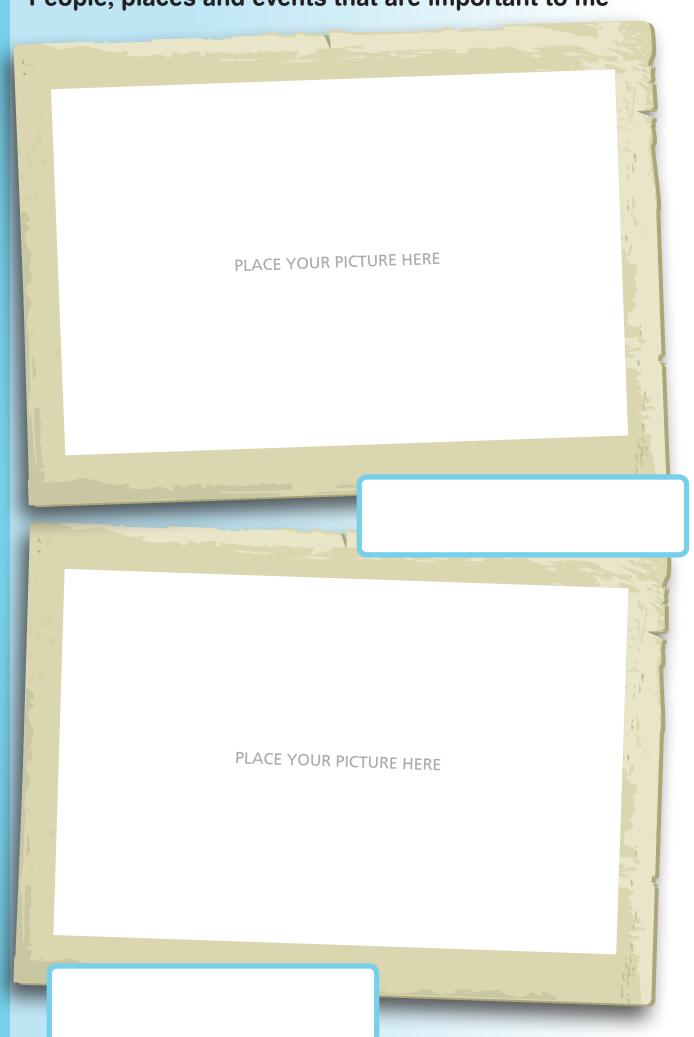
At Night
Likes: At night my usual routine is:
At night it helps me to settle if:
Dislikes: The things that bother me and make me anxious are:
The things that cause me discomfort are:

# Part 2 Getting to Know Me

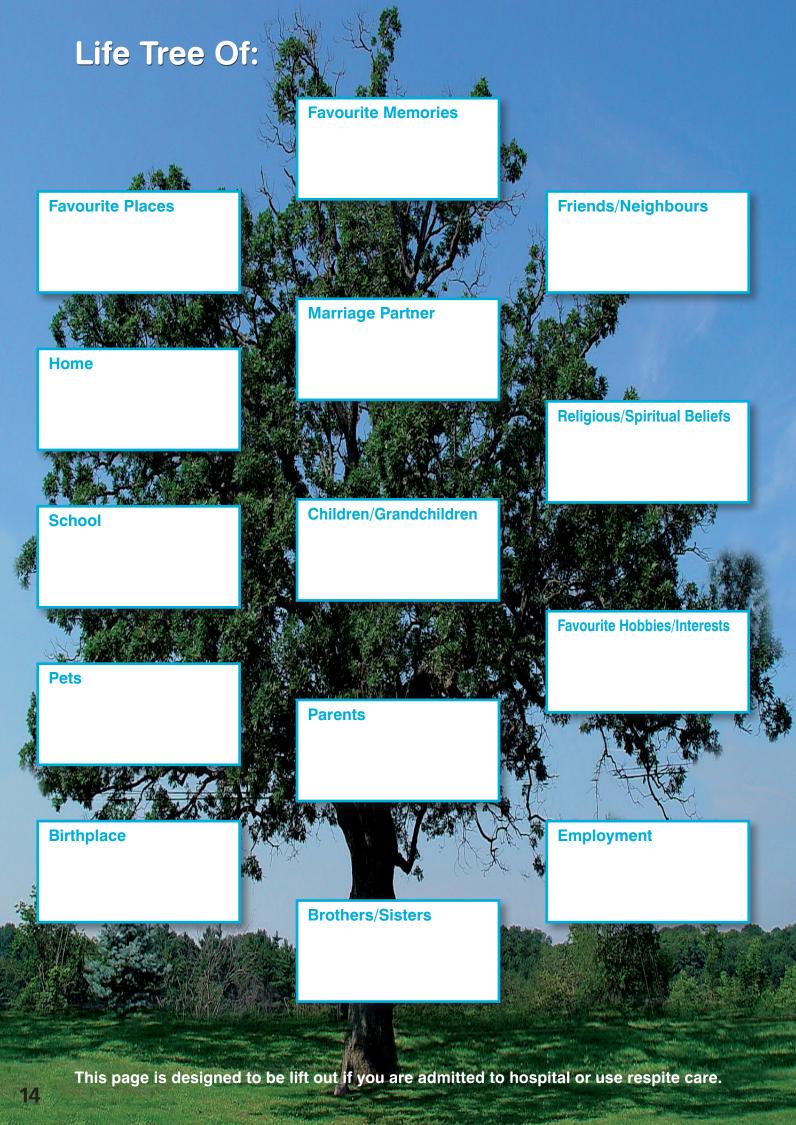
Tart - Grotting to ranow wie
My family and friends are:
In my working life, I did:
My regular routines are:
My regular routines are: (e.g. morning walks, meet friends, watch rugby.)
(e.g. merning walke, meet mende, water ragely.)

I really like and enjoy:
My favourite food and drinks are:
A good day far ma is when
A good day for me is when:
A good day for me is when:
A good day for me is when:
A good day for me is when:
A good day for me is when:
A good day for me is when:
A good day for me is when:
I have a bad day when:

# People, places and events that are important to me







# **Section 3**

# **Care Planning Information**

# **Medical Contact Details**

Title and symbol	Name	Contact Number
GP		
Community Dementia Nurse		
Dementia Advisor		
Chemist		
Dentist		
Optician		
Occupational Therapist		
Physiotherapist		
District Nurse		
Speech and Language Therapist		
Consultant Psychiatrist		
Dementia Link Worker		

# **Current prescription record**

Date	Drug	Dose	Frequency	Authorised/ Confirmed by

# Dates, appointments, messages and comments

Date and Time	Event

# Dates, appointments, messages and comments

Date and Time	Event
Date and Time	FAGIIC
l	
-	

# **Personal Events Section**

2013

		Ja	anua	ary					Fe	bru	ary					N	larc	h		
M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S	M	T	W	Т	F	S	S
	1	2	3	4	5	6					1	2	3					1	2	3
7	8	9	10	11	12	13	4	5	6	7	8	9	10	4	5	6	7	8	9	10
14	15	16	17	18	19	20	11	12	13	14	15	16	17	11	12	13	14	15	16	17
21	22	23	24	25	26	27	18	19	20	21	22	23	24	18	19	20	21	22	23	24
28	29	30	31				25	26	27	28				25	26	27	28	29	30	31

			Apr	il						Ma	y						Jun	е		
M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S
1	2	3	4	5	6	7			1	2	3	4	5						1	2
8	9	10	11	12	13	14	6	7	8	9	10	11	12	3	4	5	6	7	8	9
15	16	17	18	19	20	21	13	14	15	16	17	18	19	10	11	12	13	14	15	16
22	23	24	25	26	27	28	20	21	22	23	24	25	26	17	18	19	20	21	22	23
29	30						27	28	29	30	31			24	25	26	27	28	29	30

			Jul	y					Α	ugı	ıst					Sep	ten	nbe	r	
M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S
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8	9	10	11	12	13	14	5	6	7	8	9	10	11	2	3	4	5	6	7	8
15	16	17	18	19	20	21	12	13	14	15	16	17	18	9	10	11	12	13	14	15
22	23	24	25	26	27	28	19	20	21	22	23	24	25	16	17	18	19	20	21	22
29	30	31					26	27	28	29	30	31		23	24	25	26	27	28	29
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7	8	9	10	11	12	13	4	5	6	7	8	9	10	2	3	4	5	6	7	8
14	15	16	17	18	19	20	11	12	13	14	15	16	17	9	10	11	12	13	14	15
21	22	23	24	25	26	27	18	19	20	21	22	23	24	16	17	18	19	20	21	22
28	29	30	31				25	26	27	28	29	30		23	24	25	26	27	28	29
														30	31					

# **Personal Events Section**

2014

		Ja	anua	ary					Fe	bru	ary					N	larc	:h		
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		1	2	3	4	5						1	2						1	2
6	7	8	9	10	11	12	3	4	5	6	7	8	9	3	4	5	6	7	8	9
13	14	15	16	17	18	19	10	11	12	13	14	15	16	10	11	12	13	14	15	16
20	21	22	23	24	25	26	17	18	19	20	21	22	23	17	18	19	20	21	22	23
27	28	29	30	31			24	25	26	27	28			24	25	26	27	28	29	30
														31						

			Apr	il						Ma	y						Jun	е		
M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S
	1	2	3	4	5	6				1	2	3	4							1
7	8	9	10	11	12	13	5	6	7	8	9	10	11	2	3	4	5	6	7	8
14	15	16	17	18	19	20	12	13	14	15	16	17	18	9	10	11	12	13	14	15
21	22	23	24	25	26	27	19	20	21	22	23	24	25	16	17	18	19	20	21	22
28	29	30					26	27	28	29	30	31		23	24	25	26	27	28	29
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M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S
	1	2	3	4	5	6					1	2	3	1	2	3	4	5	6	7
7	8	9	10	11	12	13	4	5	6	7	8	9	10	8	9	10	11	12	13	14
14	15	16	17	18	19	20	11	12	13	14	15	16	17	15	16	17	18	19	20	21
21	22	23	24	25	26	27	18	19	20	21	22	23	24	22	23	24	25	26	27	28
28	29	30	31				25	26	27	28	29	30	31	29	30					

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M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S	M	Т	W	Т	F	S	S
		1	2	3	4	5						1	2	1	2	3	4	5	6	7
6	7	8	9	10	11	12	3	4	5	6	7	8	9	8	9	10	11	12	13	14
13	14	15	16	17	18	19	10	11	12	13	14	15	16	15	16	17	18	19	20	21
20	21	22	23	24	25	26	17	18	19	20	21	22	23	22	23	24	25	26	27	28
27	28	29	30	31			24	25	26	27	28	29	30	29	30	31				

# Understanding and Recognising Pain in People with Dementia



Pain is a common problem for the older person but is poorly recognised and often unresolved.

Recognising pain for the person living with dementia is made even more difficult through memory loss and communication problems.

When assessing for pain:

- Don't rush or second guess
- Check that you can be seen and heard by the person with dementia
- Try different words for pain such as sore, ache, hurt

Listen to family and carers. They will be familiar with, and able to recognise, changes in behaviour or expression that might suggest discomfort or distress.

In Gloucestershire, the following tools are recommended:

- Abbey Pain Score
- DisDAT

For a FACTSHEET and more information visit: www.gloucestershire.gov.uk/extra/dementiatraining

Pain is described as being physical, emotional or psychological in nature.

The following behaviours are some of the ways that pain may be expressed by the person with dementia:

# Physical Pain

- · Pacing or walking
- Sighing or chanting
- Repeatedly asking or calling for help or family member
- Closed or tightened eyes
- Distorted facial expression
- · Rubbing affected area
- · Rocking or holding self

# Emotional pain

- Anxious or fearful appearance
- · Crying, screaming or shouting
- Aggressive or angry

# Psychological Pain

- Quiet, apathetic, withdrawn or depressed appearance
- Distressed and crying
- Irritable
- Disrupted sleep
- · Increased confused

# There are many causes of pain:

- Loss of familiar surroundings
- Noisy, distressing environment
- Feeling isolated or separated
- Neurological change
- Cancer
- Constipation
- · Infection or delirium
- Ear or toothache

Based on Responding to pain experiences of people living with learning disabilities and dementia. D. Kerr, C. Cunningham, H Wilkinson. www.jrf.org.uk



Working together in partnership:



Gloucestershire Hospitals
NHS Trust





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# **Disability Distress Assessment Tool**

Individual's name:		
DoB:	Gender:	
NHS No:		
Your name:		
Date completed:		
Names of others who helpe	ed complete this form:	

# THE DISTRESS PASSPORT

Summary of signs and behaviours when content and when distressed

# **Appearance when CONTENT**

Face Eyes

Tongue/jaw

Skin

# **Vocal signs when CONTENT**

Sounds

Speech

# **Appearance when DISTRESSED**

Face

Tongue/jaw

Skin

# **Vocal signs when DISTRESSED**

Sounds

Speech

# **Habits and mannerisms when CONTENT**

Habits

Mannerisms

Comfortable distance

# Habits and mannerisms when DISTRESSED

Eyes

Habits

Mannerisms

Comfortable distance

# **Posture & observations when CONTENT**

Posture

Observations

# Posture & observations when DISTRESSED

Posture

Observations

Known triggers of distress (write here any actions or situations that usually cause or worsen distress)

# **Disability Distress Assessment Tool**



Please take some time to think about and observe the individual under your care, especially their appearance and behaviours when they are both content and distressed. Use these pages to document these.

We have listed words in each section to help you to describe the signs and behaviours. You can circle the word or words that best describe the signs and behaviours when they are content and when they are distressed.

Your descriptions will provide you with a clearer picture of their 'language' of distress.

#### **COMMUNICATION LEVEL\***

This individual is unable to show likes or dislikes	Level 0
This individual is able to show that they like or don't like something	Level 1
This individual is able to show that they want more, or have had enough of something	Level 2
This individual is able to show anticipation for their like or dislike of something	Level 3
This individual is able to communicate detail, qualify, specify and/or indicate opinions	Level 4

<sup>\*</sup> This is adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulty (Jones, 1994, National Portage Association).

#### **FACIAL SIGNS**

<b>Appearan</b>
-----------------

Inform	nation / instructions	Appearan	Appearance when content		Appearance when distressed			ed	
Ring	the words that best	Passive	Laugh	Smile	Frown	Passive	Laugh	Smile	Frown
	describe the facial appearance	Grimace	Startled	l Fi	rightened	Grimace	Star	tled	Frightened
		Other:				Other:			

#### Jaw movement

Information / instructions	Movement when content			Movement when distressed		
(Ring) the words that best	Relaxed	Drooping	Grinding	Relaxed	Drooping	Grinding
describe the jaw movement	Biting	Rigid		Biting	Rigid	
	Other:			Other:		

#### Appearance of eyes

Inforn	Information / instructions		Appearance when distressed						
Ring	the words that best	Good eye co	ntact	Little ey	e contact	Good eye co	ntact	Little ey	e contact
	describe the appearance	Avoiding eye	contact	Closed	eyes	Avoiding eye	contact	Closed	eyes
		Staring	Sleepy	eyes		Staring	Sleep	y eyes	
		'Smiling'	Winkin	g	Vacant	'Smiling'	Winkir	ng	Vacant
		Tears	Dilated	l pupils		Tears	Dilated	d pupils	
		Other:				Other:			

# **SKIN APPEARANCE**

Inforn	formation / instructions		Appearance when distressed				
Ring	the words that best	Normal	Pale	Flushed	Normal	Pale	Flushed
	describe the appearance	Sweaty	Clammy		Sweaty	Clammy	
	• •	Other:			Other:		

Information / instructions	Sounds when	content		Sounds when d	listressed	
Ring the words that best	Volume: high	medium	low	Volume: high	medium	n low
describe the sounds	Pitch: high	medium	low	Pitch: high	medium	low
Write down commonly used sounds (write it as it sounds;	Duration: short	intermittent	long	<b>Duration</b> : s	hort inte	rmittent
'tizz', 'eeiow', 'tetetetete'):	Description of	sound / vocalis	ation:	long		
	Cry out Wa	il Scream	laugh	<b>Description of so</b> Cry out Wa		
	Groan / moan	shout	Gurgle	Groan / moan	shout	
	Other:			Other:	Snout	Gurgle
				Other.		
SPEECH Information / instructions	Words when o	content		Words when dis	stressed	
Write down commonly used	TVOIGO WHOTE	, ontone		Words Wildir an	J.1 0000u	
words and phrases. If no words are spoken, write NONE						
Ring the words which best	Clear Stutte	rs Slurred	Unclear	Clear Stutters	Slurred	Unclear
describe the speech	Muttering	Fast	Slow	Muttering	Fast	Slow
	Loud	Soft	Whisper	Loud	Soft	Whisper
	Other, eg. swear	ring	·	Other, eg.swearing	9	·
HABITS & MANNERISMS						
Information / instructions	Habits and ma content	annerisms wh	ien	Habits and man distressed	inerisms wh	nen
Write down the habits or						
mannerisms, eg. "Rocks when sitting"						
Write down any special comforters, possessions or toys this person prefers.						
Please Ring the statements	Close with strang	gers		Close with strange	ers	
which best describe how	Close only if kno	wn		Close only if know	n	
comfortable this person is with other people being physically	No one allowed close			No one allowed clo	ose	
close by	Withdraws if touched			Withdraws if touch	ed	
BODY POSTURE						
Information / instructions	Posture when	content		Posture when d	listressed	
Ring the words that best	Normal	Rigid	Floppy	Normal	Rigid	Floppy
describe how this person sits and stands.	Jerky	Slumped	Restless	Jerky S	Slumped	Restless
•	Tense Still	Able to ac	djust position	Tense Still	Able to	adjust positio
	Leans to side	Poor	head control	Leans to side	Poo	or head contro
	Way of walking:	Normal / Abnor	mal	Way of walking: N	ormal / Abnorn	nal
	Other:			Other:		
		when conten	t	Observations w	hen distress	sed
	Observations	Wildir Goliton		Pulse:		
Information / instructions  Describe the pulse, breathing,	Observations Pulse:	Wildin Golffen				
Information / instructions				Breathing:		
Information / instructions  Describe the pulse, breathing, sleep, appetite and usual eating pattern, eg. eats very quickly, takes a	Pulse:			Breathing: Sleep:		
Information / instructions  Describe the pulse, breathing, sleep, appetite and usual eating pattern, eg. eats very quickly, takes a long time with main course, eats	Pulse: Breathing:			_		
	Pulse: Breathing: Sleep:			Sleep:		

# **Information and Instructions**

#### **DisDAT** is

**Intended** to help identify distress cues in individuals who have severely limited communication.

**Designed** to describe an individual's usual content cues, thus enabling distress cues to be identified more clearly.

**NOT a scoring tool.** It documents what many carers have done instinctively for many years thus providing a record against which subtle changes can be compared.

Only the first step. Once distress has been identified the usual clinical decisions have to be made by professionals.

Meant to help you and the individual in your care. It gives you more confidence in the observation skills you already have, which in turn will give you more confidence when meeting other carers.

#### When to use DisDAT

When the team believes the individual is NOT distressed

The use of DisDAT is optional, but it can be used as a

- baseline assessment document
- transfer document for other teams

#### When the team believes the individual IS distressed

If DisDAT has already been completed it can be used to compare the present signs and behaviours with previous observations documented on DisDAT. It then serves as a baseline to monitor change.

If DisDAT has not been completed:

a) When the person is well known DisDAT can be used to document previous content signs and behaviours and compare these with the current observations

b) When the person is new to a carer, or the distress is new, DisDAT can be used document the present signs and behaviours to act a baseline to monitor change.

# **How to use DisDAT**

- Observe the individual when content and when distressed- document this on the inside pages. Anyone who cares for them can do this.
- 2. Observe the context in which distress is occurring.
- 3. **Use the clinical decision distress checklist** on this page to assess the possible cause.
- 4. Treat or manage the likeliest cause of the distress.
- The monitoring sheet is a separate sheet, which may help if you want to see how the distress changes over time.
- 6. **The goal** is a reduction the number or severity of distress signs and behaviours.

# Remember

- Most information comes from several carers together.
- The assessment form need not be completed all at once and may take a period of time.
- Reassessment is essential as the needs may change due to improvement or deterioration.
- Distress can be emotional, physical or psychological.
   What is a minor issue for one person can be major to another
- If signs are recognised early then suitable interventions can be put in place to avoid a crisis.

#### Clinical decision distress checklist

Use this to help decide the cause of the distress

#### Is the new sign or behaviour?

Repeated rapidly?

Consider pleuritic pain (in time with breathing)
Consider colic (comes and goes every few minutes)
Consider: repetitive movement due to boredom or fear.

- Associated with breathing?
   Consider: infection, COPD, pleural effusion, tumour
- Worsened or precipitated by movement? Consider: movement-related pains
- Related to eating?

Consider: food refusal through illness, fear or depression Consider: food refusal because of swallowing problems Consider: upper GI problems (oral hygiene, peptic ulcer, dyspepsia) or abdominal problems.

- Related to a specific situation? *Consider:* frightening or painful situations.
- Associated with vomiting?
   Consider: causes of nausea and vomiting.
- Associated with elimination (urine or faecal)?
   Consider: urinary problems (infection, retention)
   Consider: GI problems (diarrhoea, constipation)
- Present in a normally comfortable position or situation?

Consider: anxiety, depression, pains at rest (eg. colic, neuralgia), infection, nausea.

If you require any help or further information regarding DisDAT please contact:
Lynn Gibson 01670 394 260
Dorothy Matthews 01670 394 808
Dr. Claud Regnard 0191 285 0063 or e-mail on claudregnard@stoswaldsuk.org

For more information see **www.disdat.co.uk** 

#### Further reading

Regnard C, Matthews D, Gibson L, Clarke C, Watson B. Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing*, 2003, 9(3): 173-6.

Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). J Intellect Disability Res. 2007; **51(4)**: 277-292.

Distress may be hidden, but it is never silent

# **Top Tips for Carers from Gloucestershire Carers**

# **Early days**

# After the diagnosis of dementia for someone you love:

**Try not to worry.** You have become a carer. Take a deep breath. As often as you need when things feel over-whelming; retreat to the garden to give yourself a few moments of peace. Most importantly keep things in perspective and don't apportion blame to yourself or anyone else.

**Practical help.** Write a list of the skills you don't have, but probably need. Engage a recommended electrician or plumber for other jobs and make a list of handy numbers. Learn how to do simple tasks. For example, learn how to read a meter, adjust timers or check fuses.

**Transport.** Consider how getting around might be affected. Don't rush, but start thinking about whether it is time for the person for whom you care to stop driving. Enlist help to make the decision. Raise the subject with him/herself, talk to your GP, seek advice from the abbr DVLA, family and friends.

**Daily life.** Find out as much as you can about dementia. Consider the implications of caring at home, both in the immediate future and long term. Ask Social Services to put you in touch with people like Occupational Therapists who can advise about adaptions or Assistive Technology.

Accept help. As well as statutory sources of help, talk to friends, family and neighbours so

that they can understand how to help you.

**Take your time.** It is natural to feel bereft and to miss the life you once had. Things won't be quite the same again. So take your time to adjust.



# **Section 4**

# **Getting Information About Dementia**

# **Getting local information**

Managing Memory <sup>2</sup> gether:	0800 694 8800
Gloucestershire County Council:	
Adult Social Care Helpdesk	01452 426868
Registering with the Carers Emergency	
Scheme: (Adult Social Care Helpdesk)	01452 426868
Carers Gloucestershire:	01452 386283
Alzheimer's Society Gloucestershire	01452 525222
Patient Advice and Liaison Service (PALS)	
Community PALS	08450 151 548
Hospital PALS	08000 193 282

# **Information Leaflets**

Some of the Alzheimer's Society leaflets listed below have proven to be helpful:

- What is dementia?
- What is Alzheimer's Disease?
- What is Fronto-temporal dementia?
- What is vascular dementia?
- What is dementia with Lewy-bodies?
- What is Parkinson's?
- Younger people with dementia
- Maintaining everyday skills
- Staying healthy
- Advance decision
- About medication
- Benefits
- Driving and dementia
- Enduring power of attorney and lasting powers of attorney
- Financial and legal affairs
- Carers; looking after yourself
- Community Care Assessment
- How health and social care professionals can help

# Information that may be needed in the future

This is a list of some of the issues that you may need support and advice on in the future.

Your GP and others can give more information if needed. Section 5 has contact details of other sources of information.

- Nursing or Residential Home
- Home Care
- Day Care
- Respite care and breaks
- Mental Capacity Advocacy Service
- Progression of dementia
- Planning for your future care
- Preventing Falls
- Managing Pain
- Assistive Technology
- Continuing Health Care Funding
- Carer Support
- Funding for Care (Benefits)
- Holidays

# **Section 5**

# **Useful Contacts**

Advocacy		
Carers Education		
Care Quality Commission Independent regulator of health and social care in England	<b>03000 616161</b> enquiries@cqc.org.uk	
Advocacy Trust Gloucestershire (ATGlos) Provides independent volunteer advocates to help vulnerable people to protect their rights	Stroud, Cheltenham, Cots, Gloucester Forest of Dean	0845 0511203 01594 821121
Gloucestershire Older Persons' Association Independent organisation providing a voice for those aged over 50 years	<b>01453 756717</b> gopa4672@hotmail.co.uk	
PALS The NHS Patients Advice and Liaison service supports anyone with a concern regarding their NHS services.	Community PALS 0800 0151548 (Freep Hospital PALS 0800 0	hone) 0193282

Community, Charitable and Voluntary Agencies				
Age UK (National)	<b>0800 169 6565</b> (Between 8.00am - 19.00pm) www.ageuk.org.uk			
Age UK Gloucestershire	01452 422660			
Alzheimer's Society	National Telephone 0845 300 0336 www.alzheimers.org.uk Gloucestershire 01452 525222 Alzheimer's Society Gloucestershire			
Alzheimer's Society Dementia Adviser Service	01452 525222			
Alzheimer Memory Cafe UK	01452 525222			
Barnwood Trust Gloucestershire – based charity dedicated to improving the quality of life for those with complex needs	01452 614429 / 0845 5040670 www.barnwoodtrust.org			
Brunel Care Provides care and services to older people	Gloucester 01452 550066 www.brunelcare.org.uk			
Carers Direct	08088 020202 www.nhs.uk/carersdirect			
Carers Gloucestershire	01452 386283 www.carersgloucestershire.org.uk			

Citizens Advice Bureau	Gloucester and District Cheltenham, Cirencester and Tewkesbury Stroud and District from landline from mobile Forest of Dean	01452 527202 01285 652908 01242 522491 08444 111444 0300 3300650 01594 823937
Cruse Bereavement Care	National www.cruse.org.uk Gloucestershire	0844 477 9400 01242 252518
Dementia UK	www.dementiauk.org 020 7874 7200	
Independence Trust Mental Health Services	0845 863 8323 www.independencetrus	st.co.uk
Parkinson's UK  Local branch	020 7931 8080 (office) Helpline enquiries@parkinsons Gloucestershire, Swindor North Wiltshire Isw.gloucs@parkinson	n and <b>0844 225 9821</b>
Samaritans	Gloucester Cheltenham & District www.contenteddement	
SPECAL (Specialised Care for Alzheimer's)	Burford www.specal.co.uk	01993 822129
Stroke Association	National Helpline www.stroke.org.uk	0303 3033 100
Gloucestershire Village & Community Agents Free sign posting service connecting their area	For Details on local group 01452 528491 www.villageagents.org people to local service Gloucestershire Rural Community Council	.uk
Gloucestershire Young Carers	01452 733060 www.glosyoungcarers.	org.uk
Recycled Furniture (household furn	niture etc)	
Emmaus	01452 551146	
Furniture Recycling Project	01452 302303	
Reclaim	01242 228823	
Statutory Services		
Benefits Enquiry Line (Department of Work and Pensions)	<b>0800 882200</b> Disabil	ity and carers
Gloucestershire Adult Helpdesk (Social Services)	01452 426868	

Gloucestershire Community Alarm Service	Gloucester Lifelink Forest Linkline Tewkesbury Helpline Cheltenham Lifeline Careline in the Cotswolc	01452 833133 01594 812505 01684 272745 01242 264393 s 01453 825473 or 01594 812505 01594 812506			
	Stroud Careline	01453 754149			
Telecare, Gloucestershire County Council	Referrals Enquiries	01452 426868 01452 583743			
Gloucester City Homes	Freephone	0800 408 2000 01452 424344			
Gloucestershire County Council Severn Wye Energy Agency	01452 425000 www.glo 0800 500 3076				
Gloucestershire Fire and Rescue Service	Freephone www.glosfire.gov.uk	0800 1804140 non emergency			
Gloucestershire Out of Hours GP		0300 4210220			
Gloucestershire Constabulary	101	non emergency			
Hospitals	Gloucestershire Royal Cheltenham General Vale Community Cirencester Dilke Lydney North Cots Hospital Moore Cottage Hospital Stroud General Tewkesbury	03004 222222 03004 222222 03004 218494 01285 655711 03004 218640 03004 218722 03004 218770 01451 820228 03004 218080 01684 293303			
HM Revenue and Customs (VAT)	0845 0109000 www.hmrc.gov.uk				
Managing Memory <sup>2</sup> gether Carers education Free 2hr information sessions for those living with dementia at various locations	0800 6948800 managingmemory@gl www.2gether.nhs.uk/mana				
NHS Direct	0845 4647				
Pension Service	0845 6060265 www.di				
Positive Caring Programme	01452 500885 www.gld	oucestershire.gov.uk			

Registration Service (Births, Marriages and Deaths)	Appointments booked on 01452 425 000 or www.gloucestershire.gov.uk/registration		
Dementia Training and Education	Training for professionals and carers www.gloucestershire.gov/extra/dementiatraining Postive Caring 01452 500885 or 01452 426 254 postivecaring@gloucestershire.gov.uk		
Wheelchair Assessment Centre	<b>01242 713900</b> (assessment)		
Gloucestershire County Council	www.gloucestershire.gov/extra/ dementiatraining		
Transport			
Blue Badge Parking Scheme	01242 532302 bluebadge@gloucestershire.gov.uk		
Dial-a-ride/Community Community Transport Third Sector Services	Cheltenham       08456 805029         Cinderford       01594 844558         Cirencester       01285 658802         Coleford       01594 844558         www.gloucestershire.gov.uk/communitytransport       01452 426868         Gloucester       01452 627851         or       08456 805029         Lydney       01594 843809         Newent       01531 821227         Tetbury       01666 502514         Tewkesbury       01684 297209         or       08456 805029         Bream       01594 560257         Wotton under Edge       01453 542091         Dursley (Elderly & Disabled)       01453 545828         North Cotswold       01608 651115         Stroud District       01453 759005		
Shopmobility	Gloucester <b>01452 302871</b> Cheltenham <b>01242 255333</b>		
Lydcare (Formerly Lydbrook Care In The Community)	01594 860143		

# Support Services for people with dementia and their families

# **Bourton Memory Club**

Baptist Church Hall, Station Road, Bourton on the Water 2<sup>nd</sup> Wednesday of the month 1030 - 1230hrs

# Contact Val McKay 01451 810637

A cafe style environment for people with dementia and their families/carers in which to socialise and take part in activities.

# **Broadway Memory Cafe**

Methodist Church Hall, High Street, Broadway 3<sup>rd</sup> Thursday of month 1100 - 1230hrs

# Contact Signpost Broadway 01386 859029

Cafe for people with dementia and their families/carers provides an opportunity to meet other people and take in activities.

# **Cam Carers Support Croup**

GL11 Communities, Fairmead, Cam Last Wednesday of month - 1400 - 1500hrs

# Contact GL11 communities 01453 548530

peer support group for carers only.

# **Cheltenham Memory Cafe**

Municipal Offices, Promenade Cheltenham 2<sup>nd</sup> Tuesday of the month 1030 - 1200hrs

# Contact Alzheimer's Society 01452 525222

A monthly cafe for people with dementia and their families/carers in which to meet other people (incl health and care professionals,) obtain information and take part in activity.

#### Cheltenham Singing for the Brain

Bishops Cleeve Community Centre Church Road, 1<sup>st</sup> and 3<sup>rd</sup> Thursday of the month 1400 - 1530hrs - place are limited

# Please contact Alzheimer's Society 01452 525222

# **Chipping Campden Memory Club**

Badgers Field - 3rd Monday of the month - 1030 - 1230hrs

#### Contact Val McKay 01451 810637

A cafe style environment for people with dementia and their families/carers in which to socialise and take part in activities.

# **Chipping Norton**

Lights Up Art Club - Highlands, 73 Burford Road 2<sup>nd</sup> and 4<sup>th</sup> Tuesday of the month - 1045 - 1230hrs

#### Contact Dementia Web 0845 1204048

# **Cirencester Memory Cafe**

Holy Trinity Church Hall, Watermoor Cirencester Third Friday of the month 1000 - 1200hrs

# Contact Alzheimer's Society 01452 525222

A monthly cafe for people with dementia and their families, friends/carers in which to meet other people (incl health and care professionals) obtain information and take part in activity.

# **Cirencester - South Cotswold Memory Club**

Holy Trinity Church Hall, Trinity Road,

Cirencester - 1st Friday of the month - 1000 - 1200hrs

# Contact The Churn Project 01285 644779

An activity with refreshments for people with dementia and their families/carers, each month provides the chance to take part in different activity as well as obtain.



#### Countrywide

Working Age Adult Service - a dedicated service providing peer support and activities to people aged 65yrs and under with a diagnosis of dementia and their families.

Contact Alzheimer's Society 01452 525222 for further information.

# Countywide

Gloucestershire Lifestyles a range of social activities for people with dementia Contact Gloucestershire Lifestyle 01452 530184

#### **Directions**

The Oakwood, Tewkesbury Road Twigworth

1st Monday of the month - 1100hrs- lunch available at own cost - peer support group for carers whose relatives have moved in to care.

Contact Alzheimer's Society 01452 525222

# **Forest Support Group**

Various venues - last Thursday of the month 1030- 1230hrs - for people with dementia and their families/carers

Contact Alzheimer's Society 01452 525222

# **Gloucester Art Group**

Gloucester Resource Centre, Alfred Street, Gloucester -

1<sup>st</sup> and 3<sup>rd</sup> Tuesday of month 1030 - 1230hrs - an art group for people with dementia - sessions are facilitated by artists and volunteers.

Contact Alzheimer's Society 01452 525222

# **Gloucester Memory Cafe**

Gloucester Farmers Club, Greville Close - 2<sup>nd</sup> Wednesday of the month 1130 - 1430hrs - lunch available at own cost.

Contact Alzheimer's Society 01452 525222

#### **Gloucester Singing for the Brain**

Hucclecote Rugby Club, Churchdown Lane, Fortnightly on a Wednesday 1030 - 1200hrs **Contact Alzheimer's Society 01452 525222** Places are limited so please book.

#### **Harrow Hill Tea Dance**

Church Rooms, Harrow Hill Drybrook, 2nd Friday of the month - 1400 - 1600hrs

#### Contact Alzheimer's Society 01452 525222

Peer support group combined with a traditional tea dance for people with dementia.

Their families, friends and carers.

#### **Kimbrose Lunch Club**

Gloucester, St Peter's Social Club, Black Dog Way. Thursday every fortnight - 1100 - 1400hrs

Contact Elizabeth Pollock, Brunel Care 01452 550066

# **Lechlade Memory Club**

St Birinus Court

4th Friday of the month - 1030 - 1230hrs

# Contact Val Mckay 01451 810637

A cafe style environment for people with dementia and their families/carers in which to socialise and take part in activities.

# **Minchinhampton Alzheimer Cafe**

Horsfall House Day Centre, Windmill Road, Minchinhampton 2nd Thursday of the month - 1900 - 1200hrs.

#### Contact Alzhemimer's Society 01452 525222

Monthly cafe based per support group with guest speakers and the opportunity for discussions for people with dementia, their families and carers.



#### **Moreton in Marsh Memory Club**

Jameson Court - 1st Thursday of the month - 1030 - 1230hrs

Contact Val McKay 01451 810637

A cafe style environment for people with dementia and their families/carers in which to socialise and take part in activities.

# Nailsworth - Alzheimer Cafe

Christchurch Rooms, Newmarket Road, Nailsworth last Wednesday of the month - 1400 - 1600hrs Contact Alzheimer's Society 01452 525222

Monthly cafe based peer support group with guest speakers and opportunity for discussions for people with dementia, their families and carers.

#### **Newent Memory Cafe**

St Mary's Church Hall, Newent, 1st Friday of the month - 1000 - 1130hrs

# Contact Alzheimer's Society 01452 525222

A monthly cafe for people with dementia, their families and carers.

#### **Stonehouse Carers Support Group**

Stonehouse Community Centre, Laburnum Walk, Stonehouse Last Tuesday of the month - 1400 - 1530hrs.

# Contact Alzheimer's Society 01452 525222

Peer support group for carers and an activity group for people with dementia places are limited so please book.

#### **Stonehouse Singing for the Brain**

Stonehouse Community Centre, Laburnum Walk, Stonehouse - 1st and 3rd Tuesday of the month - 1400 - 1530hrs - Singing and peer support for people with dementia and their families and carers.

#### Contact Alzheimer's Society 01452 525222

Places are limited so please book.

#### Stroud Memory Club

Uplands Day Centre - 3rd Thursday month - 1400 - 1600hrs - reminiscence, friendship, music and light refreshment.

#### Contact Diane Vaughan 01453 759388

#### **Tetbury Memory Club**

The Priory Care Home - 2nd Thursday of the month - 1030 - 1230hrs.

**Contact Val McKay 01451 810637** - a cafe style environment for people with dementia and their families/carers in which to socialise and take part in activities.

#### **Tewkesbury Memory Cafe**

Tewkesbury Day Centre, Station Road, Tewkesbury - last Wednesday of the month - 1400 - 1600hrs.

# Contact Jan Worad 01684 296238

Monthly cafe for people with dementia, their families and carers in which to meet other people and obtain information.



# Acknowledgements

We would like to thank the Gloucestershire community and beyond for inspiring us to develop the Living Well Handbook. Many individuals and groups have willingly given time to review, comment on and support the production of the Handbook:

Carers representatives in Devon

Individuals living with dementia and their carers

Health and social care staff

Gloucestershire National Dementia Strategy Project Management Board

**PALS** 

Carers Gloucestershire

Alzheimer's Society Gloucestershire

<sup>2</sup>gether NHS Foundation Trust

Gloucestershire Hospitals NHS Foundation Trust

Gloucestershire Care Services NHS Trust

Gloucestershire County Council

Great Western Ambulance Service

NHS Innovations South West

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