Focus on the Person

Information about: (FULL NAME)

A form to help family carers inform the hospital staff about a person living with dementia

Who should complete this form?

This form is for family carers to complete. You are a family carer if you are a relative or friend of the person with dementia—providing care, support, and/or advocacy. You may like to complete this form with the person who is living with dementia.

What is the purpose of the form?

If your relative or friend needs to go to hospital, the information you provide in this form will help the hospital staff provide person-centred care. Person-centred care values each person as an individual.[1] Information about the person's *usual* daily routines, needs, and preferences is important when providing person-centred care.

Why is this information needed?

The person with dementia may find communication challenging within the hospital. This information can help the staff tailor care for the person.

What do I do with the form if the person for whom I provide care needs to go to hospital?

If a trip to hospital is needed, the completed form should be given to the nurses.

Please check monthly and insert dates when checked

Please request or print a new form when full

1 Brooker D (2004) What is person-centred care in dementia? *Reviews in Clinical Gerontology* 13: 215–22.

The remaining pages are for you to complete. Please tick the appropriate boxes and provide the additional information requested. Please use a black or blue pen and write in block letters. We recommend checking information monthly. Please use the 'UPDATES' sections to add any changes.

DCRC Dementia Collaborative Research Centres
Curtin University
QUT Queensland University of Technology
Sir Charles Gairdner Hospital

Translating Dementia Research Into Practice

This form provides information about:

FULL NAME

who likes to be called:

HOW DO THINGS USUALLY WORK?

1 Sleep and rest

Night time sleep: Chair ☐ 1 Bed ☐ 2 **Time:** From ☐ To ☐

What helps to settle?

Day time sleep: No ◯ Yes ◯ Sometimes ◯

Where: Chair ◯ Bed ◯ **Time:** From ☐ To ☐

What helps to settle?

More information including any special comfort measures in chair or bed (e.g. to avoid pressure)

2 Eating and drinking

Drinks: need to be thickened? No ☐ 1 **Yes** ☐ 2 Please explain:

Drinks preferences (including type and temperature)

Drinks alcohol? No ☐ 1 **Yes** ☐ 2 How often/ when:

Food: Soft only ☐ 1 Pureed only ☐ 2 Normal ☐ 3

Likes (please detail):

Dislikes (please detail):

Cultural preferences No ☐ 1 **Yes** ☐ 2 Please explain:

Intolerances No ☐ 1 **Yes** ☐ 2 Please explain:

Allergies No ☐ 1 **Yes** ☐ 2 Please explain:

Help needed? Yes ☐ 2 **No** ☐ 1 **Supervision needed?** Yes ☐ 2 No ☐ 1

Other information or prompts that help

DATE FIRST COMPLETED

UPDATES

Section number
Date
Change

Section number
Date
Change

Section number
Date
Change

HOW BEST TO AVOID FALLS

3 Getting around

Able to stand? No 1 **Yes** 2 ▶ Help needed? No 1 Yes 2

Supervision needed? No 1 Yes 2

Prompts needed? No 1 Yes 2

Other information or prompts that help

Able to walk? No 1 **Yes** 2 ▶ **Supervision needed?** No 1 Yes 2

Needs: stick or cane 1 frame 2 to hold furniture 3 support from person 4

Other information or prompts that help

4 Falls

Previous falls in last 12 months?

No 1 **Yes** 2 ▶ **How many?**

Are falls becoming more frequent? No 1 Yes 2

When are most falls? Day 1 Evening 2 Night 3

Where do most occur?

Any injuries

Any known causes (e.g. trip)

5 Avoiding falls

Please list anything usually done to help avoid falls (including equipment used such as alarm mats)

How is help requested? Unlikely to ask for help 1 Likely to call out 2 Likely to use a call bell 3

Other ways 4 ▶ Please explain

Hip protectors worn? No 1 **Yes** 2 ▶ Always 1 Daytime only 2 Night time only 3

Head protector? No 1 **Yes** 2 ▶ When?

UPDATES

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PERSONAL CARE

6 Toileting

Day time: can use toilet? No 1 ▶ **Options used** e.g. bottle, pads

Yes 2 ▶ **Any times preferred?**

Help needed?

Yes 2 No 1 ▶ Supervision needed? No 1 Yes 2

Prompts that help

Night time: any different needs? No 1 **Yes** 2 ▶

7 Bathing

Shower No 1 **Yes** 2 ▶ How often?

When?

Help needed? No 1 Yes 2

Sit or stand? Sit 1 Stand 2

Supervision needed? No 1 Yes 2

Prompts that help with showering

Shaving No 1 **Yes** 2 ▶ **Type:** Electric razor 1 Safety razor 2

Usual shaving routine

Dental Help or supervision needed with teeth cleaning? No 1 Yes 2

Dentures No 1 **Yes** 2 ▶ Top 1 Bottom 2

Denture adhesive used? No 1 Yes 2

Any concerns with wearing? No 1 Yes 2

Prompts, help or supervision needed with teeth/dentures

8 Dressing

Clothes: is any help needed? No 1 **Yes** 2 ▶ Please explain:

Preferences:

Supervision needed? No 1 Yes 2

Prompts that may help?

Footwear: is any help, supervision or prompting needed? No 1 **Yes** 2 ▶ Please explain:

Preferences or needs:

UPDATES

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HOW ARE KEY HEALTH ISSUES USUALLY MANAGED?

9 Vision

Spectacles used? No [1] **Yes** [2] When used:

Eye drops needed? No [1] **Yes** [2] For what and when:

Any other vision concerns?

10 Hearing

Deafness? No [1] **Yes** [2] Left [1] Right [2]

Aids used:

Preferences for fitting and wearing

Any other hearing concerns?

11 Pain

Any ongoing pain concerns?

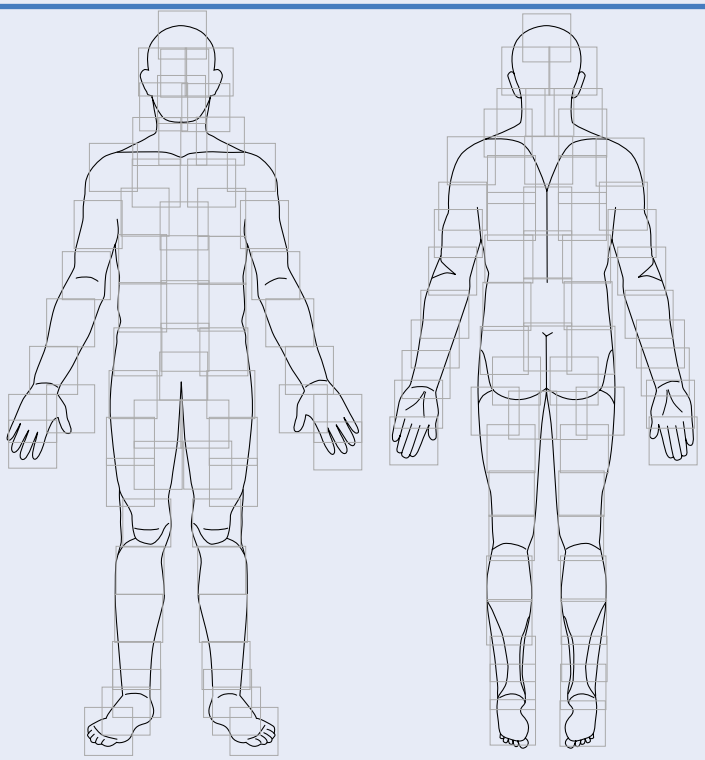
No [1] **Yes** [2]

Ways pain is shown

What makes it better

What makes it worse

Please click or mark with a cross on the diagram where pain occurs



UPDATES

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HOW ARE KEY HEALTH ISSUES USUALLY MANAGED?

12 Usual tablets and medicines

How are tablets taken? (e.g. with milk, in jam)

Are any tablets crushed? No 1 **Yes** 2 ▶ Please explain:

How are liquid medicines taken?

It would be useful to also keep an up to date list of the tablets/medicines used by the person living with dementia with this form. The following link may be useful for this purpose: www.nps.org.au

13 Agitation

Any usual agitation?

No 1 **Yes** 2 ▶

What triggers this?

Any time of day it usually occurs

What makes it better?

What makes it worse?

14 Mood changes

Do distressing mood changes or other responses occur?

No 1 **Yes** 2 ▶ Sometimes 1 Often 2

What happens and any known triggers

Responses from the staff that may help

Does resistance to care occur?

No 1 **Yes** ◯ ▶ Sometimes 1 Often 2

What happens and any known triggers
(e.g. cultural issues, care from males or females, personal space)

Responses from the staff that may help

UPDATES

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Change

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COMMUNICATION AND ADDITIONAL INFORMATION

15 Communication

Language(s) used at home

Talking Talks freely 1 Talks little 2 Never speaks 3

Preferred conversation topics/prompts (e.g. show family photos)

Preferred activities

Guidance or support needed

Frequent re-orientation and reminders helpful? No 1 Yes 2

Any body language to look for? No 1 Yes 2 ▶
(e.g. indicates need for toilet)

UPDATES

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Change

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Change

16 Anything else the hospital staff should know?

Recent significant events

Past hospital experiences

General 'do's and 'don't's

Other information

This form was completed by:

Name:

Preferred contact:

This form is developed based upon research that informs us of risks experienced by people living with dementia who are admitted to hospital. This page of the form provides information relating to that research and requires no action from carers. When there are evidence-based guidelines to address these risks, these are noted.

FIRST, there is substantial evidence that people living with dementia who are hospitalised are at greater risk of developing **delirium** (sometimes called acute confusion) than other hospital patients.[1–7] Most evidence is from studies conducted with older people. Sometimes people who have dementia have additional risks for developing delirium as well. For example, the use of a restraint or a urinary catheter is known to increase risk, whether the admission is for a medical illness, surgery, or for intensive care.[3,8] Other risks factors for delirium include those related to medicines and usual alcohol use,[3,8] the severity and type of illness and associated changes in the body (e.g, in the blood),[3,8] vision impairment,[8] and environmental issues such as a lack of visible daylight.[3]

Australian guidelines include the following recommendations to reduce the risk of delirium: **manage discomfort and pain, promote relaxation and sleep, encourage eating and drinking, avoid constipation, encourage regular mobilisation, ensure use of visual and hearing aids (as tolerated), and encourage independence**.[8]

SECOND, there is evidence that people living with dementia who are hospitalised with acute illness are at increased risk of 'adverse events' (negative outcomes) such as **falling**;[9,10] also the **development of pressure injuries, urinary tract infections and pneumonia**.[6]

THIRD, perhaps because of the risks already noted, people with dementia are at higher risk of **staying longer in hospital** than other patients.[11,12,13] For example, the development of delirium can lead to declines in independence, medical complications, and falls, as well as to delayed discharge.[5,7,9]

FOURTH, hospital patients who are living with dementia are more likely to experience **distressing behavioural responses** than hospital patients without dementia[14] or people with dementia living in the community.[15] There is a possible association between these behavioural responses and adverse events such as falls.[15]

1. Travers C, Byrne GJ, Pachana NA, Klein K, Gray LC. Prospective observational study of dementia in older patients admitted to acute hospitals. *Australasian Journal on Ageing*. 2013;33(1):55–8. (II)
2. Travers C, Byrne G, Pachana N, Klein K, Gray L. Prospective observational study of dementia and delirium in the acute hospital setting. *Internal Medicine Journal*. 2012;43(3):262–9. (II)
3. Van Rompaey B, Elseviers M, Schuurmans M, Shortridge-Baggett L, Truijen S, Bossaert L, cartographers. Risk factors for delirium in intensive care patients: a prospective cohort study 2009. (II)
4. Ahmed S, Leurent B, Sampson EL. Risk factors for incident delirium among older people in acute hospital medical units: a systematic review & meta-analysis. *Age & Ageing*. 2014;43(3):326-33 (III–3)
5. Bail K, Goss J, Draper B, Berry H, Karmel R, Gibson D. The cost of hospital-acquired complications for older people with and without dementia: A retrospective cohort study. *BMC Health Services Research*. 2015;15(1):1-9. (III–2)
6. Bail K, Berry H, Grealish L, Draper B, Karmel R, Gibson D, Peut A. Potentially preventable complications of urinary tract infections, pressure sores, pneumonia, and delirium in hospitalized dementia patients: retrospective cohort study. *BMJ Open*. 2013; 3:3002770. (III–2)
7. Fick, DM, Steis, MR, Waller, JL, Inouye, SK. Delirium superimposed on dementia is associated with prolonged length of stay and poor outcomes in hospitalized older adults. *Journal of Hospital Medicine*. 2013; 8(9): 500–05. (II)
8. Clinical Epidemiology & Health Services Evaluation Unit. Clinical practice guidelines for the management of delirium in older people Melbourne, Victoria: Victorian Government; 2006.
9. Chen X, Van Nguyen H, Shen Q, Chan DKY. Characteristics associated with recurrent falls among the elderly within aged-care wards in a tertiary hospital: The effect of cognitive impairment. *Archives of Gerontology and Geriatrics*. 2011;53(2):e183–e6. (III–3)
10. Watkin L, Blanchard MR, Tookman A, Sampson EL. Prospective cohort study of adverse events in older people admitted to the acute general hospital: risk factors and the impact of dementia. *International Journal of Geriatric Psychiatry*. 2012;27(1):76–82. (II)
11. Menendez, ME, Bot AGJ, Ring D. *Clinical Orthopaedics and Related Research*. 2013; 471:3336–48. Doi: 10.1007/s11999–013–3138 (III–2)
12. Lenzi J, Mongardi M, Rucci P, Ruscio ED, Vizioli M, Randazzo C, et al. Sociodemographic, clinical and organisational factors associated with delayed hospital discharges: A cross-sectional study. *BMC Health Services Research*. 2014;14(1):128. (IV)
13. Connolly S, O'Shea E. The impact of dementia on length of stay in acute hospitals in Ireland. *Dementia*. 2015;14(5):650–8. (III–2)
14. O'Connell B, Orr J, Ostaszkiewicz J, Gaskin CJ. Nursing care needs of patients with and without dementia admitted to hospital with fractured neck of femur. *International Journal of Orthopaedic and Trauma Nursing*. 2011;15(3):136–44. (III–2)
15. Sampson EL, White N, Leurent B, Scott S, Lord K, Round J, et al. Behavioural and psychiatric symptoms in people with dementia admitted to the acute hospital: Prospective cohort study. *British Journal of Psychiatry*. 2014;205(3):189–96. (II)

Levels of evidence, shown in the reference list as bracketed roman numerals, are specified by the Australian National Health and Medical Research Council (Aetiology). Australian guidelines (Reference 8) are a key resource for hospital staff. Evidence incorporated from these guidelines is described as 'high level' by the guideline authors.