

A Person-Centred Model of Residential Respite Care Transition Support:

Manual for partners and families



Queensland University
of Technology

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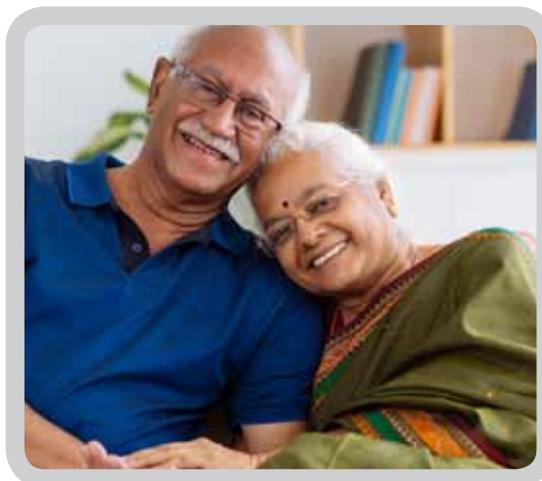
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About this manual

While residential respite care has been identified as an essential support for carers of people with dementia, as it provides family carers with an opportunity to take a break from the caring role, there has been carer reluctance to use such services. Carers have reported that factors contributing to their reluctance to use existing respite services, and in particular, residential respite care, include the perceptions that the respite experience will be detrimental to the health and behavioural stability of the person with dementia, and that carers experience feelings of increased anxiety and guilt when care is relinquished.



In response to these concerns, the Person-Centred Model of Residential Respite Care Transition (**T**ransition **S**upport: **P**erson-**C**entred **C**are **TS-PCC**) Program was developed with the aim of improving the experience of Residential Respite Care for people with dementia and their carers.

This manual has been designed to assist you, as primary carer, to prepare resources to enable clear communication about your family member's unique care needs, to care staff of any facility where care is required for your family member. This may include a brief stay at a respite care facility; or a short hospital admission. Communicating this information in a practical and systematic way will assist the care staff to understand and provide, as closely as possible, a continuation of the care provided by you at home. This manual will help you to produce exclusive resources for your family member to ensure that everyone involved in their immediate care is informed of their care needs, preferences and behaviours. The aim is to for a smooth transition from home to respite care, and back home again. These resources include those that facilitate communication about your family member's care needs and preferences ("*Getting to know you*" booklet, care flip cards, visual care plan), as well as those that will help your family member feel more settled within the residential care environment (memory book, familiar items bag). You can choose to prepare all or some of these materials as it suits you. The steps below guide you through the process of producing these items; document templates for each are available on the DCRC website.

Step 1

Complete the *Getting to know you* booklet

The *Getting to know you* booklet aims to collect vital information about your family member; it is a very important step in the production of the unique resources for your family member. This booklet will form the basis of the communication resource pack, which you will then be able to provide to the care facility.

The first section of the booklet, “*About Me*” asks for information about your family member’s personal family history, education, hobbies, favourite holiday/s, cultural and spiritual beliefs, and lifelong achievements.

The second section “*Care Needs*” sets out your family member’s personal preferences and special requirements in terms of nutrition, communication, mobility, hygiene, elimination, rest and sleep patterns.

The third section “*Special Instructions*” is concerned with your family member’s behavioural responses to various situations, as people with dementia often exhibit unique behavioural responses to varying circumstances.

A link for the template for the *Getting to know you* booklet is provided here: <http://dementiakt.com.au/resource/residential-respite-care-transitions-famcarers/> Detailed instructions on how to complete each section are contained within the template.



NB To ensure the best outcomes are achieved each admission, it is best that information in the “Getting to know you” booklet is updated for every new admission.

Step 2

Prepare the *Memory Book*

Using the first section of the *Getting to know you booklet* as a guide, you are now ready to prepare your family member's "Memory Book".

The aim of the memory book is to provide your family member with a visual connection to family and friends while in an unfamiliar environment, as well as providing care staff with prompts to aid communication beyond the care dialogue. The care staff can use the memory book to stimulate conversation with your family member while coming into contact with him/her, and it can also be used for help reduce anxiety in your family member by providing him/her with a familiar and pleasant activity.

Copies of photographs which are meaningful to your family member can be collected, scanned and inserted in the template provided. Examples of the types of photographs that could be considered are: wedding photos, current and past photos of parents, siblings, children and grandchildren, photos from favourite

holidays, and significant events throughout the person's life. It is recommended that the photographs should elicit positive memories, and they should be significant to your family member.

A brief description about each photograph (using simple language and short sentences) can be included by you or alternatively, by your family member if possible.



In addition, a brief letter to your family member can be written as a reminder that the admission is temporary and that he/she will be returning home soon. This can be inserted at the front of the memory book, and read by, or to, your family member as needed.

A good way to present the finished booklet is through use of a display folder. ***One picture should be displayed per page, with the description written below as per the template.*** Use of a display folder enables pages to be added and taken out as needed. Alternatively, the printed pages can simply be stapled together.

A link to a template for the Memory Book is provided here:

<http://dementiakt.com.au/resource/residential-respite-care-transitions-famcarers/>

Step 3

Portable Care Flip Cards

Care flip cards are designed to provide quick access to specific care details about your family member; they can be worn on a lanyard or belt by direct care givers at the care facility. Multiple sets can be prepared and provided to key personnel involved in the care of your family member (e.g. RN, personal carer, lifestyle coordinator).

The Flip Cards can be produced from the information provided in Section 2 (***Care Needs***) and Section 3 (***Special Instructions***) of the “***Getting to know you***” booklet. Details of care instructions related to Hygiene/Elimination; Mobility; Communication; Nutrition; and Rest & Sleep are included. There is also a card summarising ***Special Medical Alerts*** and ***5 Top Tips*** for meeting care needs.



The aim of the flip cards is to provide ready reference to the ***most important information*** about your family member’s care needs. This will enable the care staff to have easy and immediate access to vital information that will help them provide the best care and communication possible for your family member. It is recommended flip cards are laminated and attached to a key ring; this will enable them to be worn by care staff via attachment to a lanyard or belt.

A link to the template for the Flip Cards is provided here:

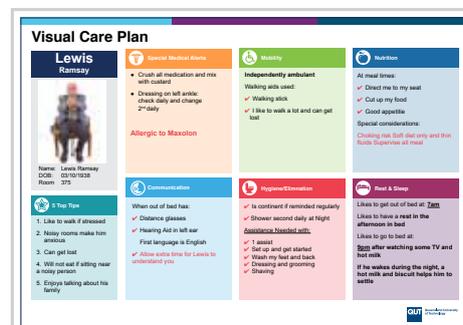
<http://dementiakt.com.au/resource/residential-respite-care-transitions-famcarers/>

Detailed instructions on how to prepare the flip cards are provided in Appendix 1.

Step 4

Visual Care Plan

Following on from preparing the flip cards, a laminated A4-sized “Visual Care Plan” can now be produced from the same information on the flip cards which have already been prepared. This can then be inserted into your family member’s care plan or displayed in a position that is easily referred to by those caring for your family member to provide quick access to information about care needs for members of the respite care team, such as inside the wardrobe door.



Step 5

“Getting to know you” Poster

The photographs used in the memory book can be displayed as a laminated A3 poster to be hung on the wall of the bedroom allocated to your family member. A brief description of each photo, as in the *Memory Book*, can be placed under each picture to act as prompts to stimulate conversation during routine care provision.



Step 6

Familiar items memory bag

Items that are meaningful to your family member can be collected from home and used to entertain him/her during admission (it is recommended that expensive and sentimental items are not included). These items can then be placed in a bag or pillow case familiar to your family member and brought to the care facility on the day of admission. Suggested items include a favourite framed photo, a DVD or CD, pack of cards, a board game, or familiar trinkets. These items can be displayed in the bedroom allocated to your family member, or kept together in their bag for use as a distraction when your family member becomes unsettled. The pillowcase can be used on your family member’s respite bed.

Use of the TS-PCC model for future respite admissions

Once you have prepared these materials they can continue to be used whenever your family member has a residential care or hospital admission. Keep them together so they are always available whenever needed.



The elements in this package should be thought of as living documents that can be added to and amended to reflect the current care needs and interests of your family member. **It is important that information be updated prior to each admission and added to as changes occur, to keep the content current and meaningful.**

For example, new photographs can be added to the *Memory Book* if significant and meaningful events have occurred between admissions. This might include events such as the birth of a new grandchild or the celebration of a special event such as a wedding anniversary.

It is particularly important that changes in care are made accordingly and new flip cards and visual care plan be created to reflect these changes.

We hope that you find these materials useful. Use whichever elements resonate the most with you.

APPENDIX 1

Detailed instructions for how to make the Care Flip Cards

Each of these flip cards are prepared using the information from Sections 2 and 3 of the “*Getting to know you*” booklet, entitled “Care Needs” and “Special Instructions”.

The aim of these cards is to provide, as much as possible, a continuation of the care provided by you at home.



When preparing the flip cards, it is important to be concise with your wording so that essential information fits on the card. (For example rather than saying “When he is anxious, he likes to take a long walk in the garden to calm down”, this may be reworded to say “Likes to walk in the garden when anxious”).

When the flip cards have been produced and printed, they can be laminated. When having the cards laminated, be sure to ask for laminator pouches for cards requiring lanyards, as these are specially designed. If you do not have access to these, then it may be possible to use a single hole-punch to create a hole to attach the lanyard.

Lanyard lamination pouches and metal rings to join the cards together are available from office supply stores.

Step 1

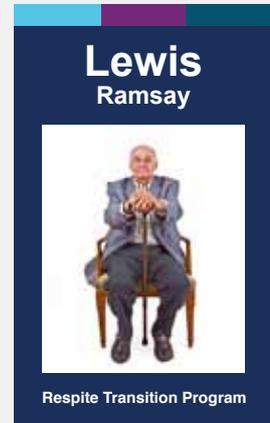
Create each card.

CARD 1: Identification

This card provides the Name, Age, and Current Photograph of your family member.

Take a current photograph of your family member with any of his/her usual “aids” used for sight, hearing or mobility (use the same photograph from the “*Getting to know you*” booklet).

For example, if he/she wears glasses, ensure these are worn at the time of taking the photograph. If your family member requires a mobility aid, such as a walking stick, make sure this is included in the photograph. If no mobility aid is used, a simple “head and shoulders” photograph will suffice. The important thing to note here, the photograph must have been taken within the past month so that care staff can easily recognise your family member and identify any aids he/she needs.



CARD 2: Special Medical Alerts

List all special care procedures (e.g. bandaging an ulcer) and allergies on this card.



CARD 3: Nutrition

Go to **questions 43 to 50** of the Getting to know you booklet.

Firstly list any **food allergies** in red.

Next – note whether your family member has a **special diet** (for example “pureed foods only”)

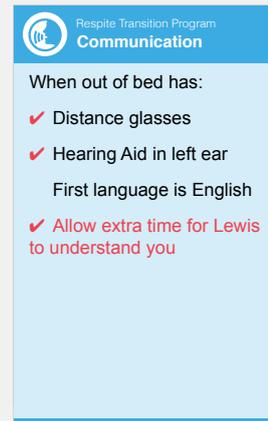
Then, the **type of assistance needed** for eating (for example, “cut up all meat and chicken”, “Can use a spoon, but no knife and fork”).

Include whether your family member has any foods he/she particularly likes or conversely, refuses to eat.



CARD 4: Communication

From Section 2 in the “*Getting to know you*” booklet (questions 51-55), abbreviate any relevant communication needs. For example: Wears glasses for reading; please make eye contact when talking to me; assist with hearing aids.



Respite Transition Program
Communication

When out of bed has:

- ✓ Distance glasses
- ✓ Hearing Aid in left ear

First language is English

- ✓ Allow extra time for Lewis to understand you

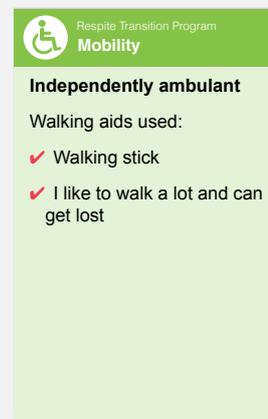
CARD 5: Mobility

Go to Questions 56 and 57 in the “*Getting to know you*” booklet.

If your family member does not require assistance to mobilise, you may write “Walks independently”.

If he/she does require a mobility aid, indicate what type of aid is used. For example, “walking stick used always”; or “needs assistance with wheelie walker”.

Include on this card, any other mobility information, such as “please assist to walk upstairs”.



Respite Transition Program
Mobility

Independently ambulant

Walking aids used:

- ✓ Walking stick
- ✓ I like to walk a lot and can get lost

CARD 6: Hygiene/Elimination

This flip card relates to questions 58 to 62 of the “*Getting to know you*” booklet; it is concerned with your family member’s hygiene and toileting needs and preferences. When completing this card, important things to consider include the level of independence your family member has with regard to:

- Showering/ bathing
- shaving (if applicable) and;
- toileting and how much assistance is required.
- Please include the type of continence aid worn (if applicable).



Respite Transition Program
Hygiene/Elmination

- ✓ Is continent if reminded regularly
- ✓ Shower second daily at Night

Assistance Needed with:

- ✓ 1 assist
- ✓ Set up and get started
- ✓ Wash my feet and back
- ✓ Dressing and grooming
- ✓ Shaving

CARD 7: Rest and Sleep

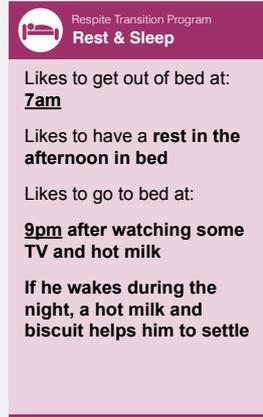
This card relates to questions 63 to 67 of the “*Getting to know you*” guide. Important things to include on this card are:

- Usual time for rising in the morning, and going to bed at night.
- Where and when your family member prefers to have a rest during the day (i.e. bed or chair, morning or afternoon, in front of the television).

You might also consider adding whether your family member wanders at night, uses the bathroom during the night, has a drink of water during the night, or any other regular night time routines/behaviours you are aware of.

Include any special bedtime routines which are usually performed at home. For example, “Prays before going to bed; has a hot milo to drink; has a snack of hot buttered toast”.

Please note, whilst some of these may not be possible (for example the hot buttered toast), it is easier for the care facility to maintain a continuation of the care, as similar as possible to that provided by you at home, when provided with this information.



Respite Transition Program
Rest & Sleep

Likes to get out of bed at:
7am

Likes to have a **rest in the afternoon in bed**

Likes to go to bed at:
9pm after watching some TV and hot milk

If he wakes during the night, a hot milk and biscuit helps him to settle

CARD 8: Five Top Tips

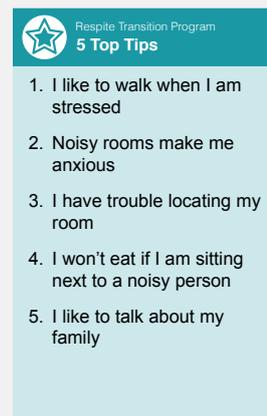
This card aims to provide care staff with the five most important things you wish to communicate about your family member’s needs/preferences.

Go through the Sections on “*Care Needs*”, and “*Special Instructions*”, to identify the five most important things you wish to communicate about your family member that will help make the transition to his/her new temporary environment easier.

Some ideas include, for example:

Behaviour/s which may be displayed by your family member when he/she is worried or anxious, and how to best calm or reassure him/her;

Presence of any food or other allergies/intolerances.



Respite Transition Program
5 Top Tips

1. I like to walk when I am stressed
2. Noisy rooms make me anxious
3. I have trouble locating my room
4. I won't eat if I am sitting next to a noisy person
5. I like to talk about my family

Step 2

Print out three sets of flip cards, and cut them to size; double-sided if possible.

Laminate each flip card; if double-sided printing is not available, place two cards back to back before laminating so the final flip card has information on each side.

Attach a metal ring. This enables the care staff to attach the flip cards to a lanyard to be worn by those immediately caring for your family member.

Step 3

Place them in your communication resource bag. Each set of cards can be used by a different person involved in the care of your family member (i.e. the registered nurse, personal carer, and lifestyle coordinator). Cards can be passed on to other staff at end of shift.

Notes

A series of horizontal dotted lines for writing notes.



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