



# Helping children and adolescents when a parent has younger onset dementia

A guide for parents, caregivers and professionals

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## Helping children and adolescents when a parent has younger onset dementia - A guide for parents, caregivers and professionals.

This guide was written by Robyn Bett and Associate Professor Jeneva Ohan. The artwork and design was created by Jean Low.

Thank you to all the clients, their families, and staff of the Brightwater Care Group who took part in the qualitative research that is the basis for this guide.

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For further information about this research and to find information and resources for families and young people when a parent has dementia or brain injury, please contact us at <https://brightwatergroup.com/research/>

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# Introduction

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Younger onset dementia impacts the whole family. This guide has been written to help parents, caregivers and professionals understand and respond to children when a father or mother has younger onset dementia.

Children and young people have less developed coping strategies for stress and life changes than adults. Parents play an important role in the development of their children's coping. When a parent develops a neurological disease, children are faced with fears and changes they struggle to understand at the same time as losing parental support.

This guide provides a list of actions for adults to help children when a parent has younger onset dementia.

No one booklet can answer all your questions, but we hope that this information will guide decision-making about children's welfare.

This guide is based on qualitative research with families and professionals and was further informed by a systematic review of international research and practice. It is not meant as a list of prescribed 'solutions', but rather to be read as information that a family might find helpful, recognising that each family has a different journey. A list of the resources we consulted is included.

**Our best wishes,  
Robyn Bett and Jeneva Ohan**

# Summary of our Research

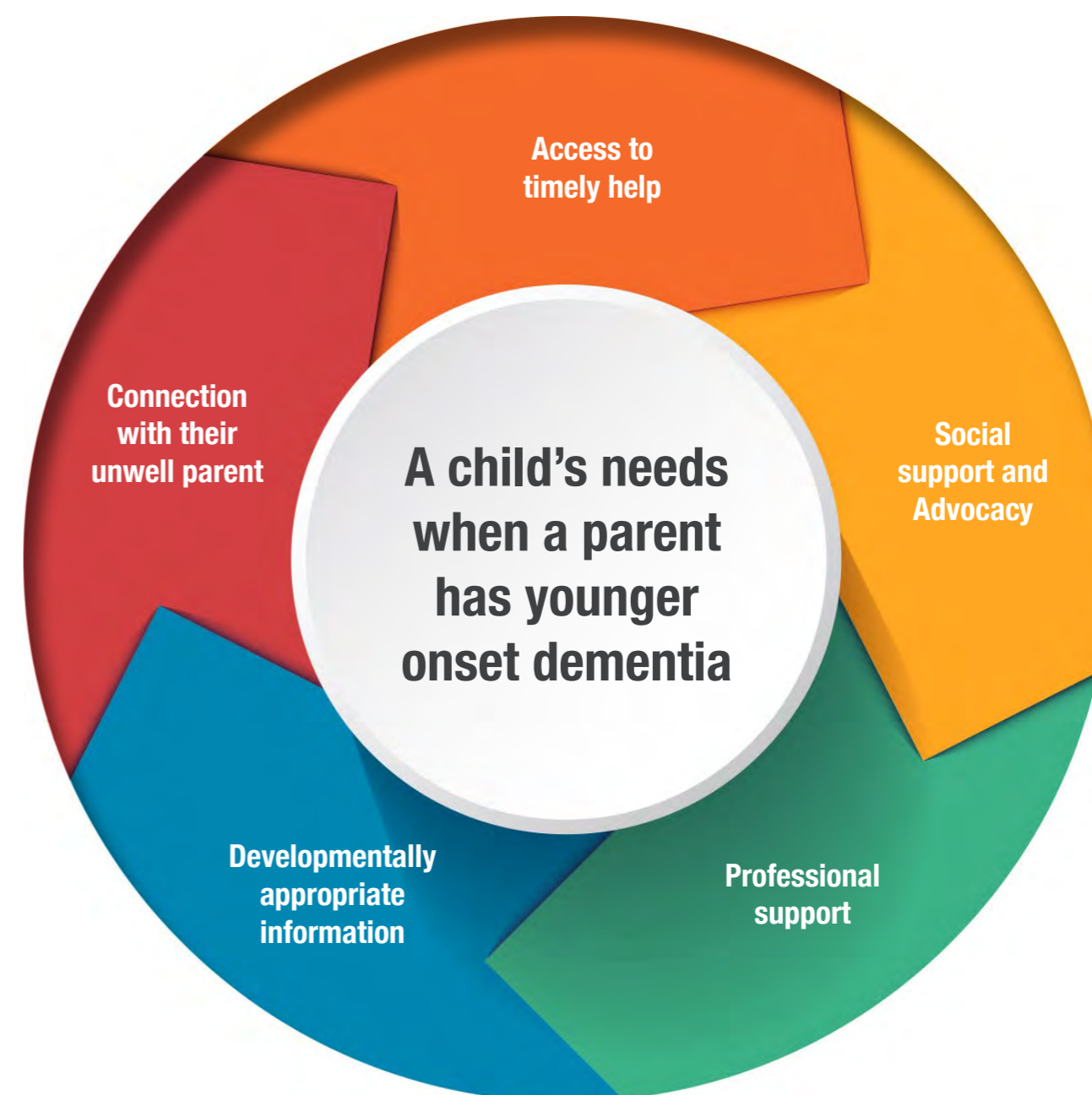
We reviewed resources and literature from around the world. We interviewed professionals, parents, co-parents, children, adolescents and young adults about their experiences. We looked for patterns of meaning and learnt about the experience of parental younger onset dementia for children and adolescents.

Young people experience changes in relationships and family roles as a parent's dementia progresses. Many have strong emotional reactions to these changes and sometimes feel alone with these big feelings. Children and adolescents report feeling separate from friends and peers because of changes in their families and find it difficult to talk about dementia, or to know who to talk to. Younger onset dementia means the family needs to focus on the parent and their illness. Focus on children's school progress, sports practice or community involvement can be neglected. Many children experience a sense of loss. We also found young people adapting to the changes in their lives, finding new ways to relate, and re-developing their vision for the future.

When a parent has younger onset dementia, the connection with their child is affected. The relationship changes and will need support to be maintained. The child will need help from family, friends and peers, and support from others with similar life experience. It is important that the child has someone to advocate for them, and has access to developmentally appropriate information. Importantly, the child may need professional support or be referred for counselling or mental health services that are available in a timely manner.

## What a child needs

Children can be helped to cope when their needs are addressed. The following diagram shows the needs expressed by our participants, and the following pages provide information to help parents, caregivers and professionals recognise and meet those needs.



# Help children understand



It is natural and important to want to protect young people from life's difficulties. When something distressing is going on, working out what to tell young people is challenging. This part of the guide will help you find ways to talk to children and young people about their parent having dementia.

Young people have the best chance of feeling stable when they are told what is happening by someone they trust. Usually, young people have noticed the changes in a parent before a diagnosis is made.

If they are not told important information directly, they have no one to answer questions and help manage their worries.

Early on children want to know about...

“Will Mum/Dad get better??”

“Can I catch it?”

“What will happen??”

“Who will look after me?”



These are difficult conversations to have, and you might find that seeking professional support, such as from a counsellor or psychologist is helpful. There are some resources listed on pages 25 of this guide that might help.

## Helpful ideas for talking with children

- If possible, choose a time when you can be calm and unlikely to be interrupted. Preferably not bedtime because after big conversations it helps for children to have some play or activity time to discharge feelings.
- It can be useful when you first tell children to have another adult with you to support you. That way children will know it is not their job to make you feel better.
- Use language your child can understand and do not provide too many details.
- Children let us know when they are ready to hear more information by asking questions or bringing up topics. Use their clues to help you decide how much to share. Young children usually need less detail than older children.
- It's okay to say that you do not know yet, and that you will let the child know when you find out more.

## Be as steady as you can

Young people take cues from adult's behaviour. Whatever their age, sit with them and talk calmly about the diagnosis so they will be better able to take in what you say.

The words that you use do not have to be perfect.

When you talk with young people you might cry. This may be difficult for you but it is okay for children to see you cry. Children might cry with you. Naming your feelings will help you keep them in check and help children feel safe.

For example:

“I am feeling confused and know I am showing it”

“I am feeling really sad right now”



**Communicating with children about a parent's diagnosis is for the child's benefit. During these conversations focus on how the young person is making sense of what you are telling them.**

**If you need to debrief about your own feelings, do this with other adults.**



## Fears a parent will die.

It is natural to want to reassure children that everything will be alright, but dementia will lead to a parent becoming unavailable to children emotionally and intellectually, and after a longer or shorter time, their parent will die.

Let them know that you will talk to them about any fears they have about death so they will not have to hide their questions, make up their own answers or take their questions to people they do not know as well.

For example:

**Child:** Will Mum be okay?

**Dad:** Mum will be safe, and there will be things she can still enjoy, but Mum's brain will not get better. She will keep changing, and we will keep missing how she used to be. Sometime in the future, Mum will die, and then we will keep on remembering her.



Parents or other family members may have philosophical and spiritual ideas that they want children to know. This may be helpful to children.

## Combine information with reassurance

When you are helping young people understand, you are also reassuring them that you are able to think about their experience. This helps children feel secure.

Reassure kids that:

- **Their parent is receiving care** – Give children practical examples. It comforts children to know their parent is being looked after.
- **The diagnosis is not the child's fault** - Always reassure children that the diagnosis is in no way connected to something they did. No matter how illogical it seems to us, a child may think “because I stressed Dad out he got dementia”.
- **They are safe** - Reassure children that they are safe, loved and will be cared for. When one parent becomes unwell, young people often fear that something bad will happen to other caregivers. It is important to remind children that other caregivers are not in danger.
- **Younger onset dementia is rare** - Some children get worried that they will get dementia when a parent has dementia. Give them lots of reassurance that they cannot catch dementia.



Here's an example of putting reassurance and information together to explain a parent's dementia to a young person.

**“When someone has dementia, they cannot get better. Dad will become more unwell and this will be hard but we will be here for each other. We are going to go through this together. No matter what, I'll make sure that you get to go to school, play with friends and do the things you like to do. No matter what, we will still be a family.”**



## Explain the impact of dementia



“Why is Mum so angry all the time?”

“Why does my Dad talk differently?”

“Dad seems so confused.”

“Why can't Mum remember anything I just told her?”



### Books and online resources can help

Children can benefit from age-appropriate explanations of what the brain does and how dementia affects brains.

There are books and online resources that can help. There are children's books that go with this guide. A full list of useful resources can be found at the back of this book.

One way to talk about dementia is using expert help, such as information found online or in books. Another way is to ask young people what they have noticed already and then talk with them about the changes they have noticed. You could also use prompts to help children begin to identify the different ways their parent is changing.

Brains, and the work they do, are hidden from sight. Young people can see a broken leg, or a scar, but they cannot see the impact dementia is having on the brain, only the result of it in a parent's behaviour. Depending on the child's age, it will probably take some time and lots of different experiences and conversations to help a child understand dementia.

Using examples that children are familiar with can help them begin to understand. Here are some suggestions for explaining what the brain does and how dementia impacts the brain.

- The brain is like a computer for the body. When a computer is damaged it can still start but it is not quite the same, it runs slower or has less memory.
- The brain is similar to the command station of a spaceship. If the command station breaks down, the crew cannot control what the spaceship does. People with dementia cannot always do what they want to do, or what they used to do, because some of the pathways in the brain have broken down.

### Professionals can help

When parents are receiving services, professionals can help children and young people understand more about their parent's dementia, and help find workarounds for the problems they face.

### Prompts to get children talking

Ask children what changes they have noticed about their parent.



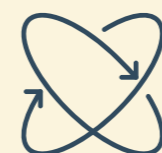
#### Behaviour (how a person acts)

For example: Mum watches TV all the time.



#### Language (how a person talks)

For example: Dad gets annoyed when he can't remember the word for things.



#### Movement (how a person moves)

For example: Dad has difficulty turning around now. He takes little steps.



#### Cognition (how a person thinks and plans things)

For example: I was talking to Mum about the plan for my birthday and she didn't know how old I was going to be.



#### Emotions (how a person feels)

For example: Dad seems happier in the mornings, he seems to get worried in the afternoon.



#### Relationships (how a person gets on with other people)

For example: Mum always wants to know where Dad is.

Thanks to AFTD's 2012 publication What About the Kids for this suggestion, [www.theaftd.org](http://www.theaftd.org)

**When you are talking with children about what they have noticed, you are helping them work through the experience. This can help them begin to come to terms with all the changes dementia is bringing into their lives.**





# Support connections



Connections with parents are vital to a child's wellbeing. Whether a child sees a parent daily, on weekends, or rarely, parents have a special place in children's minds and hearts. When a parent develops dementia, the familiar connection with a parent can become difficult to sustain.

This section is about supporting connections between a parent with dementia and a child whilst acknowledging the losses that dementia brings. Everyone's circumstances are unique, and we hope that this information can be adapted to your family or the family you are working with to benefit children.

## When a parent has changed

Unlike other illnesses, the symptoms of dementia are usually changes in behaviour, emotions and personality. These symptoms can be very confusing, embarrassing and frustrating for children and young people. The situation is often complicated by delays in diagnosis or misdiagnosis.

How dementia presents in the beginning varies. What is predictable is that struggles change over time. Some people have significant behavioural changes such as disinhibition, apathy, verbal or physical aggression. For others, language becomes impaired making

communication difficult. Dementia may also affect motor skills such as walking or taking care of daily needs. How children and young people can connect with their parent with dementia will change as the disease progresses.

A parent with dementia may lose many of the parenting roles they previously had. Changes in roles such as having a job, cooking meals or driving kids to school are more obvious parenting changes. But other more subtle changes can be equally as important.

A parent who used to be always interested in their son or daughter may stop paying attention to them. A parent who used to be a peacemaker may now be the family member who provokes arguments. A parent who would organise games and suggest play activities may now be apathetic or even worse, mess up children's activities. Parents with dementia may not be responsive to children's need for comfort when they are upset. Children may become frightened of parents whose behaviour has become unpredictable.

For all these reasons and others, children and young people may struggle to maintain a sense of connection to their parent with dementia. If children have someone they can talk to about these changes, and help to understand that it is the dementia that is causing the changes, not them or their parent, this can help free up children to remember the loving relationship with parents, and in time find ways to manage the current situation.



## Supporting connections with a parent living at home

Connecting with a parent with dementia is best achieved through activities that promote good feelings but do not require too much interaction, such as:

**Watching movies or a TV series, especially comedies.**

**Playing familiar board games, card games or video games.**

**Walking outdoors in a place the parent has always enjoyed such as the beach or the park.**



## Support for communication

People with dementia might understand conversation for a while, but talking will become more difficult. Help children learn to avoid questions that need long answers. Instead they can be taught to ask simple questions, share their own stories, and offer lots of compliments.

As language for a parent with dementia becomes difficult, help children to understand that their body language and their facial expression can still convey a lot that will be picked up on by their parent. When possible, young people can be encouraged to use touch and nonverbal gestures to communicate.

Learning to follow a parent's gaze, and making a guess about what the parent is focused on, helps create the possibility of a shared moment. Sometimes a shared gesture can create a moment of fun for example a wiggle, a wave, or a handshake.

## Roles and responsibilities

A parent with dementia is not able to supervise younger children who need constant attention. This is a matter of safety.

Older children and young adults may at times be asked to look after a parent with dementia who cannot be left alone safely. Although most families will need to do this at times, it may lead to complications in the family. Children who have to look after one parent may come to believe that they should have all the rights of an adult and do not need to accept guidance, help or discipline from other adults. Talk to children in this situation, letting them know you appreciate them helping out in this situation

for a short time, but letting them know that this does not mean they are ready to make all their adult decisions.

## Reduce conflict

Access to the TV or technology can often be a source of conflict between parents with dementia and children. If possible, get another TV/game console/tablet just for the person with dementia.

## Everyone deserves to feel safe at home

Some people with dementia develop difficulties with anger and aggression. Children and young people's experience of a parent's uncontrolled anger is distressing. Resolving this issue is very important for children's long term wellbeing.

Family violence is never acceptable even if it is due to dementia. Families can be supported by service providers to develop Positive Behavioural Support Plans and Safety Plans.

**Positive Behavioural Support Plans** involve all family members being trained to treat aggressive behaviour consistently. The plan might include keeping to consistent routines, remaining calm and responding positively during an anger outburst, recognising and managing the triggers for aggressive behaviour. Children will need the support of adult family members to participate in Positive Behavioural Support.

**A Safety Plan** is a plan for keeping everyone safe in a potentially escalating situation. Family members need to have a plan for removing themselves from potentially violent situations the moment they no longer feel safe.

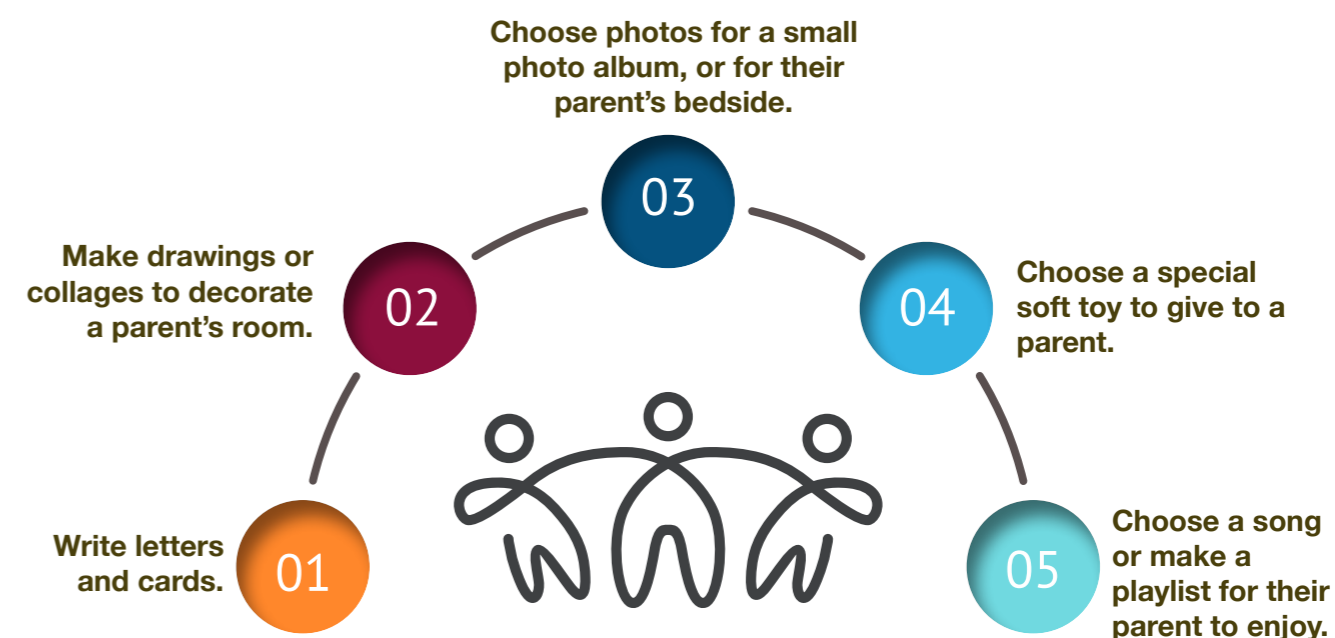
## Supporting connections with a parent living in residential care

At some stage in the progression of the illness, a parent will need to move to residential care. If there are young children in the house, this may need to happen sooner to protect children from a parent's distressing or dangerous behaviour. Encourage children to be involved while their parent is in residential care. Wherever possible children should be given the opportunity to visit, while not being forced to if it feels too difficult.

Children can have mixed feelings about visiting a parent in residential care. They want to visit, and yet at the same time feel scared of what they will see and how they will cope.

Reassure children they can change their mind at any time and nobody will be upset. If they get to the care home and change their mind, that's OK. They can try again another time if they want to.

If a child cannot visit, they can be encouraged to stay connected in other ways.





## Some ideas for helping visits go well

If you are taking children to visit their parent in residential care, it could be useful to take a family friend or other family member with you, so that children can have someone to take a break with during the visit.

Allow time for questions, but if the child does not wish to talk immediately after a visit, offer a change of subject or some quiet time.

Be prepared for children's distress – this may not be immediate and may be expressed in various forms. For example, they may become upset about something at school that would not usually affect them. Again, calm reassurance, spending time together and allowing the child to talk can help to ease their fears.

Think about each visit, and through trial-and-error, build up routines and activities that help feelings of predictability, connection and belonging.

For example:

**Showing photos on a tablet.**

**Playing a simple, familiar game.**

**Singing songs together.**

**Looking at photo albums together.**

**Looking at picture books together (Guinness Book of Records is a good one).**

**A child could bring in a collection to show – cars, cards, dolls, figurines.**

**<https://dementiatogether.online> is a website that describes resources and activities that have been tried, tested and recommended by people with dementia.**



After a visit, check-in with children how the visiting is going – is it too much, is it too little? Is there a problem about visiting that you could solve together?

As the illness progresses, some activities will not be possible any more, and other activities will need to be trialled.

**Singing songs to parents.**

**Reading aloud poems or stories.**

**Soft hair brushing.**

**Lotions rubbed into hands.**



## Supporting connections with a parent at the end of life

For many children there comes a time when parents become so changed that spending time with parents becomes too sad. Caregivers face a delicate balance in supporting children to maintain connections whilst allowing allowing children to opt out of visits.

It is helpful for children to have the opportunity to visit a parent when the parent is close to the end of life. Children might need encouragement and support to do this, however, older children and adults tell us that they were glad they had the opportunity to have some final visits.

**This finishes our section on supporting children's connections with their parent with younger onset dementia.**

**Losing a parent is very painful at any age, and the next section provides guidance on providing emotional support for children**



# Offer emotional support



Feelings unfold for children in response to the many ways in which a parent's dementia can change a child's life.

It is normal for children to feel sad, angry or scared at times when they are faced with these changes.

## Expressing feelings with words

Adults use words to express feelings more than children do. Often children (and adolescents!) do not talk about how they feel. They give one-word answers or say something like, "I miss playing with him" or, "I don't know". Children who are not talking about how they feel are **not necessarily "in denial" or holding it in**. There are lots of ways that children express themselves without words.

## Help children talk about feelings.

An adult caregiver can help children talk about feelings by:

- Offering children time for their questions and feelings. Children may not take you up on this, but it lets them know you are available. Sometimes just knowing that there is someone to talk to helps calm emotions.
- Having regular talking times such as during chores or car rides. Remember that children may express themselves in only two or three words and that is OK.
- Sharing your own feelings as a model for children.
- Finding an opportunity for family therapy, or engaging the child in some counselling of their own.

## Expressing feelings through art and play

Children express how they feel in their play. Through play, children discover and experiment with their world. It is important for a child's development.

When younger and school-aged children experience a big change in their life and/or trauma, play can become their main way of expressing feelings. The best thing about play is that children love to do it.



## Time-in with children

Children love to play anyway, but if you want to find a way to connect with a child during a difficult time, putting aside some time each day to play something they choose can help. For example, make it 10 minutes each day after dinner.



## Self expression as children grow

- Older children are not necessarily doing the creative play they used to. Some will talk about emotions but others can express themselves in different ways. Art forms can encourage self-expression, for example:
  - Painting
  - Drawing
  - Clay
  - Music (voice, instrument)
  - Drama (e.g., making 'movies' at home)
  - Writing

Letting young people know that you **appreciate, and want to nurture** their self-expression is just as **important to their development** as encouraging play for younger children. Let teens introduce you to their favourite music, YouTube clips or Tik-Tok challenges.



## A note about caretaking behaviour

Some children respond by trying to hide their own feelings, and look after others. While this might be a short term relief, it can have long term negative consequences for children who miss out on their childhood.

If your child is showing a lot of caretaking for others, then try:

- Encouraging the child to do age appropriate fun activities.
- Praising them for silliness and fun.
- Giving them defined roles for care-taking, so that they have a certain 'job' that is age-appropriate and know helps the family. Outside of this, they can do other activities.

### Responding to worries

If your child shares a worry, try to listen to what they are saying fully without dismissing it. If there is information you can provide to help or correct the basis of their worry, then do so, but do not offer false reassurances. Offering a hug, and saying "I'm glad you shared this with me" can be helpful.



## Practical ways to provide emotional support

Children respond to family crises in different ways. Some show strong emotions such as fear, anger, irritability, or worry. Others might start behaving in ways that are problematic for parents and others such as defiance, yelling, or 'talking back'. Some children and young people might have a delayed reaction. They seem like they are coping okay at first, but then show these emotions or behaviours later.

### How to help

- Try to keep to normal routines as much as possible.
- If time is limited safeguard some of the time you spend together.
- Use consistent and clear rules and boundaries with predictable consequences for unacceptable behaviour. Give these calmly.
- Show your child warmth, appreciation, and acceptance.
- Include an activity that the child enjoys into their weekly routine such as sport, dance or drama.
- Think about how the child likes to spend time (time with you, getting to school early to play with friends, going to the playground after school) and find ways to include enough of these activities into each day or week.

## Understanding children's distress

Dementia is not like a bout of the flu. There is often a long process of reaching the correct diagnosis, finding support, and eventually seeking full-time care for the affected parent. The child lives through the emotional strain of these changes, not for weeks or months, but for years.

People with younger onset dementia experience noticeable changes in physical, cognitive and emotional functioning. These changes will affect children's relationships with parents and their emotional development. They may feel restless or unhappy because they do not know how to cope with the changes.

Children may mourn the loss of the way their parent was before the dementia brought changes into their lives.

Children are in the process of developing coping strategies, and are usually focused on themselves and their own needs. They may begin to blame themselves for what they feel is going wrong in their family, not linking the difficulties with the adjustment to dementia. For all these reasons children may be at risk of developing anxiety or depression. The following two pages provide suggestions about seeking professional help if you are worried about how children are coping.

## Reach out for help if you are worried about how kids are coping

### FAMILY THERAPY

Family therapy provides an opportunity for everyone in the family to talk about what is working well and what is difficult in the family. Family therapy can help come up with new ideas for dealing with the difficulties.

01

### COUNSELLING IN THE NON-GOVERNMENT SECTOR

Many non-government agencies provide children's counselling services via a sliding scale of fees according to income. Some agencies also provide parent counselling and support. Some of the agencies that provide children's counselling services in Perth are Mercycare, Communicare, Anglicare, Wanslea and Relationships Australia.

02

03

### YOUTH COUNSELLING

In acknowledgement of the increasing developmental pressures of adolescence, there are targeted services for this age group including Headspace and YMCA YCounselling (12-25 year olds)

### COPMI (CHILDREN OF PARENT'S WITH A MENTAL ILLNESS)

Children's counselling can also be accessed through COPMI programmes that provide specialised support for children with a parent with a mental illness. Although these services will not be appropriate for all families, there will be some for whom they are appropriate and helpful. The Mental Health Commission of Western Australia fund COPMI programs.

COPMI services are provided by a number of agencies. Contact Arafmi WA, Wanslea, CLAN, MIFWA or Carers WA.

### MENTAL HEALTH CARE PLANS

Your GP can also be a point of contact for accessing counselling for children. GPs can create a Mental Health Care Plan which provides a certain number of Medicare-subsidised sessions per calendar year with a private psychologist. There is usually a gap payment between the cost the private psychologist charges, and the rebate you get from Medicare.

04

05

### Child and Adolescent Mental Health Services (CAMHS)

- If a child's emotions or behaviour problems are causing them to struggle or feel unwell in their daily life, your GP or school psychologist can refer your child to Child and Adolescent Mental Health Services (CAMHS). CAMHS are community based clinics that provide services for some children and adolescents who are assessed as having marked difficulties in their daily life.

### Safety planning

- If a child or young person is threatening to self-harm, suicide or abscond, it is important to take them seriously. Young people need someone safe nearby when they are feeling like this. Avoid arguing with young people during this time as they may not be thinking clearly. They need you to stay strong, and keep them safe until they start to feel better. If you do not feel you can keep a young person safe you should take them to a hospital Emergency Department.
- In the Perth metropolitan area children under 16 years can present to Perth Children's Hospital ED.
- Young adults (16 plus) can present to the hospital ED's in their area.
- In regional areas, people of any age can attend their local hospital ED.

Everyone, families and professionals can get help and advice in a mental health crisis by calling Mental Health Emergency Response Line (MHERL)

- **1300 555 788 (Metro)**
- **1800 676 822 (Peel)**
- **1800 552 002 (Country/Rurallink)**

### Phone Support for young people

#### Headspace

Support for young people aged 12 to 25, and their families. Telephone and web chat available, as well as local headspace centres.

**1800 650 890 (7 days: 9am – 12.30am AEST )**  
**Headspace.org.au**

#### Kids's Helpline

Free qualified counselling service for young people aged 5 to 25 (24 hours)

**1800 551 800**  
**Kidshelpline.com.au**

### Phone Support for everyone

#### Beyond Blue (24 hours)

Free online and telephone support for anyone feeling anxious or depressed

**1300 224 636**  
**beyondblue.org.au** or  
**healthyfamiliesbeyondblue.org.au**

#### Lifeline (24 hours)

Support for anyone in a crisis situation

**13 11 14**  
**Lifelinewa.org.au**

#### Suicide Call Back Service (24 hours)

Professional support for anyone who is feeling suicidal, worried about someone else or who has lost someone to suicide.

**1300 659 467**  
**Suicidecallbackservice.org.au**

Further information on mental health services and supports in Western Australia is available at the Mental Health Commission's website  
**www.mentalhealth.wa.gov.au**





# Increase social support



## Resources and practical support

A family may need help in ensuring that basic needs are met in the areas of work and finance, medical care, housing, education and child care after a parent is diagnosed with dementia.

- Contact Dementia Australia and the YOD Hub
- Consider the **Wanslea Children and Parent Support Program (CPS)**

This is a home-based visiting program designed to build the capacity of families to care for their children during stressful times including parent illness. Phone: 9245 2441

Children may need special services or support, or help to connect with community resources that provide them with social support and structured activities. Many of these issues may take some time to sort out.

Sources of support for children can include

- **School**
- **Local government**  
Check out your local government services. Many local government agencies provide Kid's Clubs, Youth Group Activities, assistance with transport, libraries, gyms, and help to pay for costs associated with children's sporting activities.
- **Counselling services**



## Building resilience together

Focusing on building resilience is helpful for children long term. Resilience helps children thrive in tough situations. The experience children have within their family is one way of building resilience. (Other factors include the child's temperament, their experiences at school, and in their community).

Ways that families build children's resilience are:

- **Making sense and meaning from challenges**
- **Adapting to changes together**
- **Prioritising each other and closeness**
- **Talking through problems together**



### Having fun

Having a store of positive experiences and memories for children helps buffer the inevitable challenges that children face as they continue through life.

Family traditions promote a sense of belonging. The child has the feeling of belonging to a unique family in which they are a special and valued member. What traditions did the family have before a parent's illness, and are they still happening? Do the traditions need changing to adapt to the new situation? Are there others traditions the family would like to start? Scheduling family traditions into the calendar each year can help family unity. Some examples include special holidays, birthday traditions, visiting family and summer holidays.

Family activities help children have fun in the family, promoting closeness and positive feelings. These provide regular predictable ways for families to enjoy each other and stay connected as children get older and lives get busier.



## Adapting to change

We have described some of the changes children face when a parent has dementia. Here are some other changes that children may face.

### Changes in the relationship with a parent or carer who is not affected

Some children report that their relationships with their other parent or carer changes too. Caregivers may become overprotective in response to a crisis in the family resulting in children feeling frustrated. Other carers might

rely more on children for support resulting in children feeling overburdened. The stress and worry experienced by the well parent as they try to manage all the changes in the family can be interpreted by children as that parent not having time for them, or being cross with them.

### Changes in the relationship between parents

The relationship between parents changes after one member of the partnership develops dementia. There may be more stressors and disagreement and these will result in changes to how children relate to parents. Keep arguments away from children and remember to tell children that disagreements are not their fault.

### Changes in friendships

Childhood friendships can be disrupted by a diagnosis of dementia in the family, leaving children feeling less connected to their peer group. They may feel that their friends are in a different 'space' to them, and that the usual concerns do not matter to them at the moment. They may feel that no one really understands what they are going through. They may not want to ask friends over any more as they may be embarrassed by the behaviour of their parent.

Talk with children about their friendships, and find out what is important for them. Consider talking with parents of children's close friends, and seeking their support for the friendship.

### Changes at home

A parent's dementia will also lead to changes in routines at home. In time all the jobs that used to be done by the parent have to be covered in another way. Everyone might need to pitch in. Children are better with discrete jobs that have a beginning and an end, and can be learnt and repeated, such as taking the rubbish out, hanging the washing, emptying the dishwasher, cleaning the car. Expect to have to remind children to do these tasks or have a roster for them.

### Helping kids manage changes

There is no quick fix or magic process to resolve these challenges. However, making time to talk, finding out what's important for children and young people and how they are feeling about the changes continues to be important. Feeling respected and understood goes a long way towards finding solutions.

The overall approach that your family adopts to dementia is the most important message you send to your children. They will see in your words and actions that changes are recognised as symptoms of dementia, and they are no one's fault.

The way parents and caregivers use self-care and the support of family and friends is a model for children. They will benefit from all positive examples of coping.



Parenting is hard at any time, and parenting through an illness can feel overwhelming. What can help parents at this time?

The following services provide parenting support in Western Australia:

- Anglicare WA
- Meeralinga
- Ngala
- Communicare
- Relationships Australia
- Uniting WA

Triple P parenting courses are currently free for all parents through the WA Department of Education.

# Advocate at school

## School is so important.

Children spend a lot of their awake life at school.

When a parent has an illness, school provides children with a needed sense of belonging to their community, normalcy, routine, and structure. In addition, education itself is provided at school.



But your child might find it hard to be as successful at school as they used to. This might be because...

- They do not have the same level of parental support in learning (e.g., practicing reading, times tables)
- They are distracted by worrying about the parent and not attending to their lessons.
- They feel disengaged from their friends as now their challenges are shifting, and they feel 'different', or do not feel supported.
- They might get teased because of the parent's changes.

Each child, family, and school is different.

## You are this child's best advocate

Working with your child's school is crucial. Without discussion, the school will not know how children are affected, what to look out for, and/or develop a plan to help.

By talking with your child's school, you are not only helping, you are also being their advocate, and modelling for your child how to advocate for themselves.

## Discussing the illness or diagnosis with your child's school

Parents often think about how to talk with their child's school about their own or a co-parent's neurological diagnosis. This is a personal decision, and what works for your family and is in the best interests of your child might differ from what works for another family. Here we offer some ideas to think about and guidance that might be helpful in making this personal decision.

### Who should I speak to?

#### Who spends the most time with my child?

Your child's teacher is most likely to be the person spending the most time with your child, and therefore would benefit from knowing about what could be affecting your child's behaviour and learning at school.

#### Who do I feel comfortable talking with?

There might be a central person, like a Deputy Headmaster, school nurse, or counsellor, with whom you feel comfortable speaking. This person could serve as your contact person.

#### You could talk with more than one person,

depending on how your child's school is organised and what is in your child's best interests. For example, you could request a joint meeting with a teacher and school counsellor.

### What should I say?

Knowing what information your child's school needs to best support your child at school can be challenging to answer.

Some information you might like to consider discussing:

The parent's **diagnosis, and what that means for your child at school.** For example:

- You might have less time or ability to help your child with homework, even though you really value education.
- The child's parent with dementia may look different and you know your son/daughter is worried about being teased.

**Strategies you think could help keep your child on track with work outside the classroom,** for example:

- The possibility of a homework club.
- For you and the teacher to have a school-home communication book in which the teacher records homework that can be easily checked.

If you cannot think of any strategies, maybe others at the school can.

**What you are hoping for your child at school.** For example:

- Hope that your child learns that school and home are working as a team.
- Hope that your child experiences understanding, and that school is a safe place.

Express that you are **open to changing strategies**, and realise that new issues might arise. Let the teacher know how to get in contact with you, and ask how it is best to contact them.

On pages 36 and 37, you will find a sheet with these ideas started that you might find helpful to fill out.

## I know what I want to say... How might I go about saying this?



### Should I mention this to my child?

Being honest with children is important in building a solid relationship. Depending on their age, they might not be involved in the discussion or the decision making process.

Letting the child know who you have spoken to about what, and why (e.g., what you are hoping to achieve for your child) not only builds honest communication, but also shows the child that you are their advocate.

## Developmental considerations

Although this section has been designed for primary school-aged children, it can also be useful for other age ranges.

**Infants, toddlers, and pre-schoolers:** You do not yet have school to discuss these issues with, but you might still wish to talk with any other childcare providers. In this case, you might find some of this still helpful in guiding what you want to say.

**Older children and adolescents:** Older children and adolescents might not want to discuss these issues with you or their school, but would still benefit from this discussion. Think about teaching them to be advocates for their own needs, and modelling for them how to do this by involving them in some of these decisions and discussions. You could both try advocating together, or one at a time. For example, you might sit down with an adolescent and problem-solve who to talk to, and what is important to say. We have included a separate resource for parents who wish to involve their children in these decisions and/or discussions.

## Primary School: What I'd like to tell my child's school

You can fill this in if you think it would be useful for you to organise your thoughts. You can add, change, or delete any sections. Different families will have different needs. If you have more than one child, you might also like to make a different sheet for each.

**01** The **diagnosis of dementia and what that means for my child at school**. You might include a) how the illness impacts the parent, and b) how the illness affects your child at school.

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**02** **Strategies that you have found helpful, or might find helpful**. You might have some ideas as to what would work for you and your child (such as introducing the school counsellor and opening the door to communication; a homework club; emailed reminders for forms), or you might not have any, in which case you could suggest trying to brainstorm ideas. If you are open to new ideas, then you might add this so that the teacher knows.

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**03** **What you are hoping for your child at school**. What are you hoping to achieve in sharing this with the school? Are there any particular goals or hopes that you have for your child at school?

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**04** Express that strategies might need to change, and new issues might arise. Advise the teacher **how it is best to get in contact with you, and ask how it is best to contact them**.

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## Middle & High School: What we'd like to tell the school

You can fill this in if you think it would be useful for you to organise your thoughts. You can add, change, or delete any sections. Different families will have different needs. Many heads are better than one – so try involving both caregivers and children/adolescents in completing this.

**01** The diagnosis of dementia **and what that means for me at school**. You might include a) how the illness impacts on the parent, and b) how the illness affects you at school.

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**02** **Strategies that you have found helpful, or might find helpful**. Depending on how the parent's dementia impacts on you at school, you might have some ideas as to what would work to support you (e.g., speaking with a school counsellor, access to a homework club). If you do not have any, in which case you could suggest trying to brainstorm ideas. If you are open to new ideas, then you might add this so that the teacher/school knows.

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**03** **What you are hoping for at school**. What are you hoping to achieve in sharing this with the school? Are there any particular goals or hopes that you have for this school year or term?

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**04** Express that strategies might need to change, and new issues might arise. Offer the teacher **how it is best to get in contact with you, and ask how it is best to contact them**.

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This material is based on.

Ohan, J. L., Eaton, K., & Corrigan, P. W. (2016). *Starting the Conversation: Do you want to talk about your child?* [Unpublished therapy manual, based on the Honest, Open, Proud Program]. School of Psychological Sciences, University of Western Australia.



# Consider developmental stages

At different developmental stages, children understand and process information and emotional challenges differently. Here are some suggestions for supporting children of different ages.



## Infants and toddlers

When an adult caregiver has a diagnosis of dementia, a baby will experience the family's distress and changes in routine. Babies may become agitated.

**At this age, physical communication is most important.** Help by providing a lot of physical contact and reassuring attention to the baby.

**Maintain a baby's routine** for physical needs as best you can, such as feedings, sleep schedules, walks and playtime. Even if the same person cannot always be there for the baby, the same routine can happen.

Let other caregivers, such as staff at the day care centre, know what has happened so they can understand changes in the baby's behaviour and provide extra comfort and reassurance.

## Pre-schoolers

Reassure children that it's OK to play even though they are sad. Toddlers' magical thinking may at times lead a child to believe they caused the illness. Help by providing lots of reassurance and physical contact.

Recognise that children's daily frustrations – in dressing, eating, playing, etc. – may be more intense because of their feelings about the dementia. Children will respond better in a time of change if the limits they are used to remain in place. **Learning to manage reasonable disappointments, having loving limits, and living with a healthy routine helps a child develop self-confidence.**

Read picture books of children coping with challenges. Talk about the characters, how they felt and why they behaved the way they did. Let other caregivers and teachers know what is happening so they can understand and soothe the child's distress.

## Primary school aged children

Rules and fairness are very important to primary school children. Children expect the world to be fair, and they react with distress when situations seem unfair. A diagnosis of younger onset dementia is not fair. Adult caregivers who can acknowledge what is unfair, disappointing or difficult help children cope. Let children vent their disappointments and then turn the conversation to what is possible. Be creative about second-best plans.

Children might suffer from more illnesses, aches and pains. Their sleep or appetite may be disturbed and their concentration and activity levels may be reduced.

Work with the school to manage a child's workload during very difficult times, and then get support from the school to help your child catch up.

Look for opportunities to counter any worries a child may have that they caused the dementia or that they are making it worse in some way. Remind children that dementia is rare, and that their other caregivers are well.

Encourage sports and active play in order to lessen a child's anxiety and physical tension. Encourage art, music, dance, singing, crafts and other expressive processes. Support children to make gifts or contribute in ways to help their parent.

## Adolescents

A major developmental task for teens is the establishment of their own identity. This frequently causes conflicts in relationships with parents. Adolescents might feel conflicted about pursuing their own goals when they know they are needed to help out at home. Continuing with activities outside the family, such as sports, hobbies, study or travel plans helps adolescents manage worries and sadness about their parent.

Fulfilling responsibilities in the family can help adolescents develop a sense of positive identity. However running parallel can be feelings of resentment about increased responsibilities at home. Adolescents want to be treated like adults at times but they still need adult advice and help.

Contact with other young people in similar situations is very important. Contact Dementia Australia family and carer support.

A family crisis can help adolescents become determined to create a life for themselves that their parents could be proud of.

# Resources

## For Children

Chambers, B., Harborow, K., & Mort, E. (2017). *This is my family*. B. Chambers.

Chow, T., & Elliot, G. (2012). *Frank and Tess – detectives! A children's activity book about frontotemporal degeneration (FTD)*. Dementiaability. <http://research.baycrest.org/files/Frank-and-Tess-Detectives-.pdf>

Dementia Australia.(2013). *My Grandmum, my Papu, my Grandma and me*. [www.youtube.com/alzheimersaustralia](http://www.youtube.com/alzheimersaustralia).

Fox, M. (1984). *Wilfred Gordon McDonald Partridge*. Omnibus Books.

Karst, P. (2000). *The invisible string*. Hachette Children's Books.

Moore, L. (2018). *My book about brains, change and dementia*. Jessica Kingsley Publishers.

Muthukumaraswamy, J. (2019). *Audrey's Dad*. Picton Press.

Ohan, J., & Bett, R. (2021). *Jordan's Mum*. Brightwater Care Group.

Pat-a-cake. (2019). *Find out about: Feelings*. Hachette Children's Books.

Silver, D. M., & Wayne, P. J. (2013). *My first book about the brain*. Dover Publications Inc.

Truly Blessed Ink. (2007). *I know you won't forget*

Watkins, R., & Anelli, L. (2016). *One photo*. Penguin Random House.

Young, K. (2017). *Hey, warrior! A book for kids about anxiety*. Hey Sigmund.

## For Adolescents and Young Adults

Cotter, D., Lopez, L., Kelleher, E., Coughlan, H., & Cannon, M. (2016). *Journey through the brain: A colouring book*. Royal College of Surgeons Ireland.

Lawrinson, J. (2017). *Before you forget*. Penguin Random House.

Nichols, K., & Chow, T. (2018). *Dementia in the house: A Canadian website with the purpose of navigating a loved one's dementia with solutions and support from experts and friends*. <http://dementiainthehouse.com/>

## For Adults

The Association for Frontotemporal Degeneration. (2012). *What about the kids?*

## Useful Websites

The Association for Frontotemporal Degeneration (USA) <http://www.aftdkidsandteens.org>

Dementia Australia <http://www.dementia.org.au>

Dementia in my family (2016) <https://dementiainmyfamily.org.au/>

Alzheimer's Association (2022). Inside the brain: a tour of how the mind works. <http://www.alz.org/alzheimers-dementia/what-it-alzheimers/brain-tour>

## Resources Consulted

Denny, S., Morhardt, D., Gaul, J., Lester, P., Anderson, G., Higgins, P., & Nee, L. (2012). Caring for children of parents with frontotemporal degeneration: A report of the AFTD task force on families with children. *American Journal of Alzheimer's Disease and Other Dementias*, 27(8). [https://doi.org/ 10.1177/1533317512459791](https://doi.org/10.1177/1533317512459791)

Gelman, C., & Rhames, K. (2020). "I have to be both mother and father": The impact of Young-onset dementia on the partner's parenting and the children's experience. *Dementia*, 19(3), 676–690. <https://doi.org/10.1177/1471301218783542>

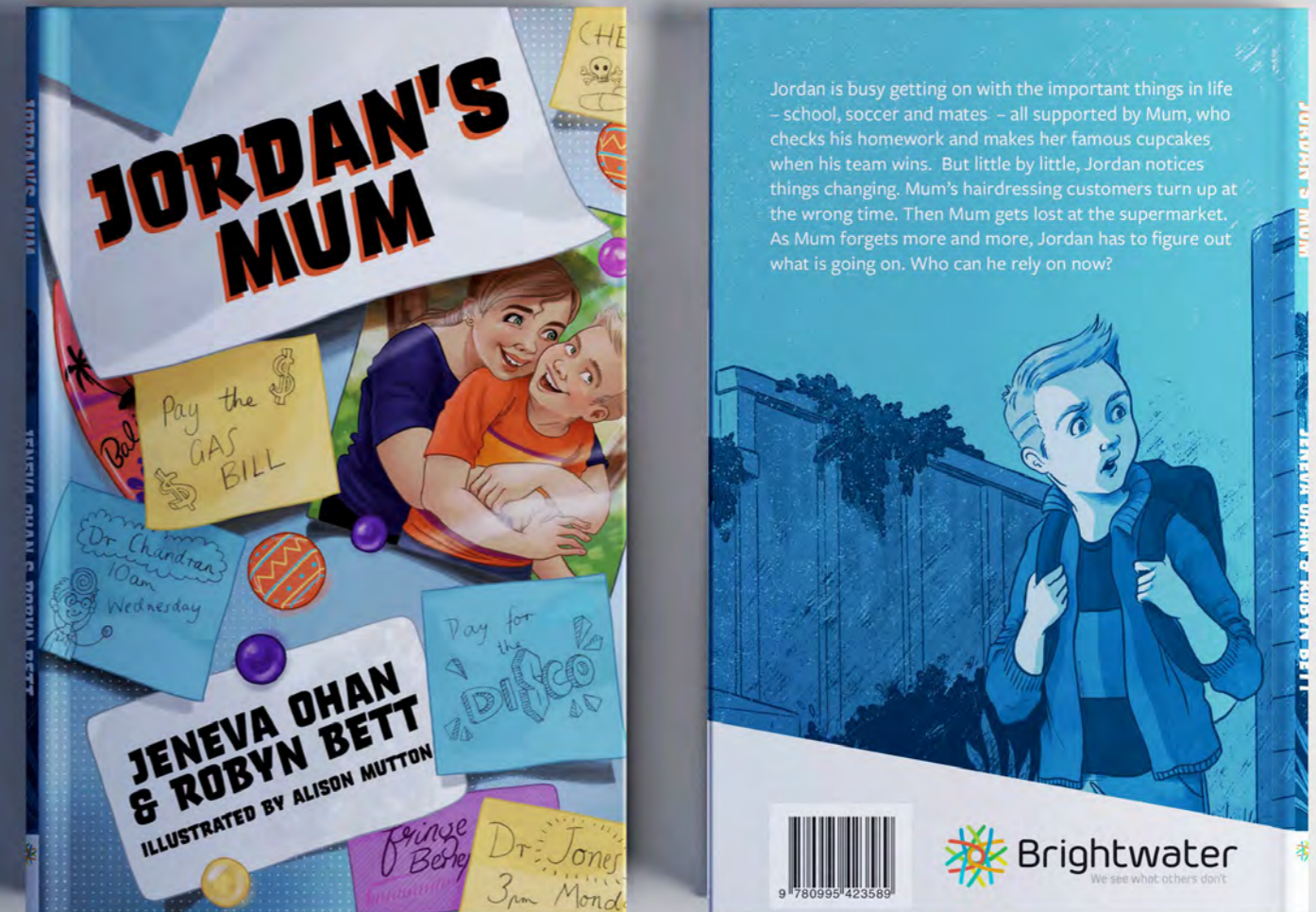
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Hutchinson, K., Roberts, C., Roach, P., & Kurrle, S. (2020). Co-creation of a family-focused service model living with younger onset dementia. *Dementia*, 19(4), 1029–1050. <https://doi.org/10.1177/1471301218793477>

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