

DEMENTIA CARE

A Guide for Carers & Families



In 2021, there
are an estimated
472,000
Australian's living
with dementia



Home Instead
To us, it's personal

WELCOME TO YOUR GUIDE FOR CARERS & FAMILIES

This booklet has been developed by Home Instead to help people caring for those with dementia, it:

- **Explains what dementia is and how it may affect people.**
- **Suggests ways a carer can provide practical support.**
- **Provides tips for communication and activities specific to supporting people with dementia.**
- **Includes information about where to find additional resources for carers.**

Home Instead

Home Instead provides high quality in-home care services to support ageing adults to remain living independently in their own homes.

Home Instead CAREGivers provide a range of services including companionship, personal care, housekeeping, meal preparation, medication reminders, transport for appointments, shopping or errands.

From 2 hours up to 24 hours, seven days a week, Home Instead CAREGivers are trained to provide assistance to people living with dementia or other age-related conditions.

Home Instead provide specialist dementia care and deliver a range of specialist dementia training programs, not only for their professional CAREGivers, but also for families, carers and communities.

For more information visit HomeInstead.com.au

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WHAT IS DEMENTIA?

A diagnosis of dementia can have an emotional effect on the person diagnosed and their family and friends. The aim of this guide is to give carers a better understanding of dementia and provide a guide on how to care for people living with dementia.

In 2021, there are an estimated 472,000 Australians living with dementia. Dementia is not a normal part of the ageing process and, whilst age is a risk factor, dementia can affect adults of all ages. However, dementia is the single largest cause of disability in people over 65 and one in four people over the age of 85 has dementia. Each week, there are more than 1,800 new cases of dementia diagnosed in Australia. This is equivalent to approximately one person diagnosed with dementia every six minutes.

Dementia is a progressive disease that affects the brain, resulting in nerve cells and brain tissue death. This affects a person's memory, intellectual abilities, social skills, and emotional reactions. It can also result in changes in personality, and affect a person's ability to maintain relationships.

Types of dementia

Dementia is a term that describes the symptoms of a large group of degenerative diseases of the brain. There are over 70 different types of dementia, however the most common forms of dementia are Alzheimer's disease and Vascular dementia.

Alzheimer's Disease

Is the most common form and the most widely known dementia. It accounts for between 50–70% of all diagnosis. Alzheimer's disease occurs when the nerve cells deteriorate in the brain due to a build-up of 'plaques' and 'tangles' which, actually results in the death of a large number of brain cells over a period of time.

Vascular Dementia

Is the second most common form of dementia accounting for up to 20% of all dementia diagnosis. Vascular dementia is the broad term for dementia associated with problems arising from a lack of circulation of blood and oxygen to the brain. Risk factors associated with vascular dementia include high blood pressure and thickening of the arteries. Vascular dementia may appear similar to Alzheimer's disease, and it is possible to have both Alzheimer's disease and vascular dementia.

There are many other different less common forms of dementia such as, dementia with Lewy bodies, alcohol-related dementia (Korsakoff's syndrome), and frontotemporal dementia (often called 'frontal-lobe dementia'). A thorough medical examination can assist in identifying the specific dementia diagnosis. Knowing the diagnosis can help family members better understand and cope with their situation.



STAGES OF DEMENTIA

Every person with dementia is unique, and no two people have the same symptoms or deteriorate at the same rate, and their abilities may change from day to day, or even within the same day. What is certain though is that their cognitive abilities will deteriorate, sometimes rapidly over a few months or in other cases more slowly and gradually over a number of years.

The early stages of dementia are often only apparent in hindsight. At the time it may be missed, or put down to old age, or overwork. The onset of dementia is usually very gradual, and it is often impossible to identify the exact time it began. In this stage, people with dementia retain some insight into their situation, but become more confused and forgetful. They may begin to lose language skills, have trouble handling money and paying bills, forget once familiar tasks and may experience personality changes.

The middle stages of dementia are when the problems of memory loss or confusion become more apparent, and have a greater impact on a person's ability to maintain their independence. They may forget or not recognise family and friends, repeat themselves often, and have problems sequencing tasks like putting on clothes or the steps required to have a shower or prepare a meal.

The later stage of dementia is when the person has become profoundly disabled and unable to manage their daily living activities requiring full care and assistance with tasks such as eating, washing, dressing and toileting.

Socialisation and support are important at all stages of the dementia journey, but they are a key intervention during the middle stages.

Structuring the day, arranging activities, and preventing isolation are important goals.

It is important to remember that not every person with dementia will go through every stage. However, these three stages provide a useful description of the general progression of the disease.



HOW CAN I SUPPORT A PERSON LIVING WITH DEMENTIA?

Caring for a loved one with dementia poses many challenges for families and carers. You may experience a variety of emotions including anger, grief, or shock, and you may be overwhelmed at times. However, the more information and support you have, the better you can navigate the road ahead.

Person-centred care

Every person with dementia is unique and their journey with dementia will be a very personal one. This means that there is no 'one-size-fits-all' approach to planning for their care needs or activities for purpose or pleasure. It is important to provide care which is person-centred whereby the care is appropriate, meaningful and unique to each individual. The care should focus on what someone can do, not what they can't do, helping the person to feel valued and promoting their self-esteem.

When a person with dementia feels safe, secure and valued, they are able to maintain their independence for longer and engage in their environment more effectively. Building a relationship between you and the person with dementia is essential to providing quality person-centred care.

People with dementia primarily experience problems with memory and thinking. They find it difficult to retain new information and they rely on past experiences to make sense of the present. By learning about and understanding the life journey of a person with dementia, that is knowing his/her stories, routines, and likes and dislikes – you can create a unique 'person-centred' approach that will help you provide quality personalised care. This person-centred approach will also assist you to better manage any issues and generally improve their quality of life.



WAYS OF PROVIDING PERSON-CENTRED CARE

The three most common communication strategies are: Reality Orientation, Validation Therapy and Reminiscence Therapy.

Reality Orientation

The aim of Reality Orientation is to gently bring someone who is disorientated or confused back from their world to their present reality by gently guiding them to an awareness of who they are, where they are, and the present time and date. This therapy works best for people with **early stages** dementia who recognise the concept of time and date. A tool to assist with Reality Orientation is a reality board. This is usually a whiteboard or noticeboard hung where it can be easily seen. Each day, the whiteboard is used to record important information including the date, the day of the week, the weather, and key activities for the day or week such as visitors or appointments. Every time the person with dementia becomes disorientated or confused the carer can redirect them by using the information on the whiteboard to re-orientate them to the present

Validation Therapy

Validation Therapy enters into the reality of the person. In this way empathy is developed, building trust and a sense of security with the person with dementia. Validation Therapy is implemented by acknowledging the person's view of reality; and encouraging the validation by really listening and asking questions.

Acknowledging and validating the reality of a person with dementia can assist in preventing behavioural symptoms of dementia and allow them to enjoy revisiting a time or place where they were happy and content. Gradually you can re-orientate or distract them back to their current time and place.

Reminiscence Therapy

Reminiscence Therapy is widely accepted as being a beneficial communication therapy for people with dementia. By capturing the life journey of someone with dementia you will be able to build a deeper one-on-one relationship with them. Reminiscence is enjoyable for most people and can create many positive emotional experiences for all involved. We all reminisce from time to time, and for someone with dementia this can be a therapeutic event as they struggle with remembering more recent events.

Talking with people with dementia about their lives can create a positive emotional experience, reduce stress and provide a better quality of life. There are three techniques for gathering information. Ask questions, observe surroundings, and talk with family and friends. Reminiscence sessions should be easy going and light. Music, photos and objects can help enhance memory gathering.

As you gather information about a person's life journey, organise it into a journal. This can be a binder, notebook or scrapbook. Be sure to organise and separate the material into several categories, such as childhood, young adult, marriage and family, career etc. This makes it easier to add information.



Reminiscing is about giving the person with dementia a sense of value, importance, belonging, power, and peace. It can take place at any time in a number of ways:

Visually; looking through family photo albums, looking at objects that have meaning, for example discussing a favourite item of clothing, or the history of an ornament or trinket, or a favourite painting.

Music; listening to familiar tunes from the radio or CDs and discussing the memories that the music triggers or singing to the music.

Smell or taste; smelling favourite flowers or foods or using smell kits, or different foods as memory triggers for discussion.

Tactile; touching objects and feeling textures which are familiar or relate to past activities and interests, or actively involving them in activities such as painting, pottery or planting/weeding in the garden.





COMMUNICATING EFFECTIVELY WITH A PERSON WITH DEMENTIA

Effective communication is where a thought or idea is passed correctly from one person to another and they acknowledge its meaning. Losing the ability to communicate can be frustrating for people with dementia, their families, and carers. As the disease progresses the ability to communicate may gradually reduce. They may find it difficult to express themselves and to understand what others are saying. Use a combination of verbal and non-verbal methods to effectively communicate with someone with dementia.

Non-verbal communication

Non-verbal communication is an important tool to help you listen to and communicate more effectively with people with dementia. As much as 93% of meaning can be derived from our body language and tone/pitch of voice.

People with dementia may lose the ability to effectively communicate their thoughts verbally and may use their behaviour and other emotions to communicate.

When communicating with someone with dementia it is important to remember that all behaviour is a form of communication.

We all use non-verbal communication and body language to convey messages. People with dementia will read and react to your body language.

Below are some tips to help you communicate more effectively with someone with dementia:

- Be aware of your body language and attitude. For example, agitated movements or a tense facial expression may cause upset or distress, and can make subsequent communication more difficult.
- To gain a person's attention, limit distractions and noise, and maintain eye contact with them. Always try to speak to them at their eye level so they can see your expression clearly.
- Provide simple choices. Ask one question at a time – yes or no questions work best. Visual cues and prompts are a good way to increase understanding.
- Never argue or raise your voice. Arguing or shouting will only increase levels of frustration and agitation.
- Listen with your ears, eyes and heart. Always strive to listen for the meaning and feelings that underlie the words.

As dementia progresses, a person's reality often becomes one of the past and they may retreat back in time. Trying to reorientate a person with an altered reality can cause distress and trigger behavioural symptoms of dementia.

Alternative communication approaches will help you to build trust and provide support. You may already use these therapies without realising that you are or when they can be most effective.

The key to providing quality care for someone with dementia is the relationship between the person and their carer. When implementing communication therapies, it is crucial to know and understand the personality and life story of the person with dementia as this will make communication strategies more effective.



UNDERSTANDING BEHAVIOURAL SYMPTOMS OF DEMENTIA

Caring for a person with dementia can be challenging and requires patience and flexibility. One of the most distressing aspects of caring for someone with dementia can be the changes in behaviour that can sometimes occur. It is important to note that physical illness, pain or discomfort of any kind can trigger a change in behaviour and this may not be easily identified if the person with dementia cannot identify the discomfort or communicate it to you.

Always discuss any changes in behaviour with your doctor, who will be able to check for illness or pain and provide treatment.

You may encounter behaviours that are uncharacteristic or even odd, and this can be particularly upsetting when someone is behaving in a way that is completely out of character. Try to remember that the behaviour is not deliberate and may be a result of changes taking place in the brain.

It is also important to remember that all behaviour is a form of communication, particularly for people with dementia as they find it difficult to verbally express their needs, wants and feelings, and may express such things through their behaviour.

A change in behaviour may also be a result of changes in their environment, health, or even a change in medication.

Simple activities, such as taking a shower may become too difficult as the ability to recall the steps required during the showering process may be lost. As a direct result of the changes taking place in the brain, a person with dementia may react in a catastrophic way to some situations or present a range of different behavioural symptoms of dementia. This behaviour could include vocal outbursts or actions such as hallucinations, paranoia, or even violence. Every person with dementia is unique and will experience dementia in their own way and this may not involve any behavioural symptoms.

The more common changes in behaviour presented by people with dementia can include:

- Apathy and/or depression
- Refusal
- Repetition
- False Accusations
- Wandering
- Aggression
- Sexually inappropriate behaviour

Coping with changes in a person's behaviour can be upsetting for family and carers. It is important that you understand a range of techniques that you can use to overcome the challenges that the behaviour may present. You may even need to use several techniques at once. The key is to remember that the behaviour is out of the person's control and though they may not appear to be, they are in need of reassurance and empathy.

Aggressive behaviour is usually an expression of anger, fear, or frustration. Try not to take this personally and remain calm at all times, however hard it becomes. If you become angry or impatient, they will sense this and their behaviour may be exacerbated, escalating the situation.

Techniques to manage changes in behaviour

Giving simple choices helps a person feel in control.

People experiencing dementia are often confused and may feel they have no control in their lives and use behaviour as a means of trying to regain control. If a person becomes angry, offering simple choices may calm them down and allow them to feel more in control. You can assist them by breaking down a task into simple steps or simple choices, and guide them through a task which may have overwhelmed them such as getting dressed or taking a shower.

Distraction is a technique where you change the focus of the person away from whatever is distressing them to something that is more positive. You can distract them by talking about a different subject or engaging them in an activity that they enjoy. For example, offering them something to eat or drink, or direct them to an activity, for example watching TV or pointing to a photograph, or a painting, and asking them about its history or meaning. Don't underestimate the part you play in understanding their behaviour and finding ways to help them overcome their frustration or agitation to help build their self-esteem. By focusing on them you will find that you are able to support them and provide interest in their day.

Remember, help is available for people with dementia and their carers through the services listed at the end of this booklet.

Stimulating activities for people living with dementia

Creating activities that both engage and stimulate someone with dementia can be challenging. Any activity you plan needs to be meaningful and appropriate to them. Meaningful activities are important to create a sense of purpose and accomplishment and reaffirm a person's individual strengths and skills. The key is to be flexible and creative. Engaging someone with dementia in activities that they enjoy means that they are more likely to participate. Even if they only have a short attention span, you can repeat the activities at a later time.

Engage them in an activity/routine that you know that they enjoy e.g. walking, gardening, knitting, reading the newspaper, watching sport on TV etc.

Look at photographs together or recall a story from their past and discuss what the person can remember providing prompts along the way. Don't put them on the spot to remember every detail or precise events. Just let them enjoy talking about whatever they remember.

Everyday tasks can turn into meaningful activities and engage someone with dementia. For example, hanging out or folding washing, sweeping up leaves, weeding the garden or peeling potatoes whilst you are preparing a meal, are activities that are purposeful and can help someone feel worthwhile and engaged in their own daily life. Accomplishing simple activities may seem inconsequential to some, but can be a satisfying accomplishment for someone with dementia. To encourage someone with dementia who is reluctant or disinterested to participate in an activity try to: Start the activity on your own; Give simple instructions; Simplify or modify the task into single steps; Invite them to help you with an activity.

Research has shown that people with dementia benefit significantly from remaining in familiar surroundings for as long as possible. To achieve this you may need the assistance of professional CAREGivers from Home Instead.



Examples of longer term activities:

Plant and care for a boxed mini-garden. Encourage and assist them to plan and plant their favourite flowers and plants in a boxed garden. To start this activity visit the local garden centre to choose seedlings for the planter box. Make the most of the senses during this activity. Encourage smell, touch, visual and auditory stimulation.

Garden scrapbook. Create a garden scrapbook by going through garden magazines and calendars and cutting out pictures that are of interest to paste into the scrapbook. You could also collect and press flowers and visit local public parks or gardens to take photographs for inclusion in the scrapbook. Not only is this a pleasurable ongoing project, the scrapbook can also become a resource for initiating conversation with family and friends.

Activity boxes or sensory boxes are a great way in which to engage a person with dementia. Fill the boxes with tactile items that are personal to them. For example, if the person enjoyed sewing the box could be filled with swatches of material, pin cushions, a tape measure, cotton reels etc. For those that enjoyed fishing they could have a box with reels and floats or the person who has travelled extensively could have a box of travel memorabilia including tickets, maps and photos.

Personalised photo puzzle. Together, sort through family photos to choose a suitable one that can be copied and enlarged to A3 size. Glue the photo to a piece of cardboard, cut out the shapes to form a jigsaw.

The demands of caring for someone with dementia should not be underestimated, however, it can be rewarding and comforting to know that you are providing them with a safe and familiar environment. Over time you will face new challenges and have to adapt your care to meet their changing needs. Whilst at times you may feel alone and isolated it is important that you are aware and make contact with organisations and support networks that can assist you to make the journey easier for both you and the person with dementia.



NUTRITION AND FOOD AFTER A DEMENTIA DIAGNOSIS

Nearly half of all people diagnosed with dementia have lost weight in the year prior to their diagnosis, with that loss contributing to frailty, falls and ill health.* Understanding and supporting nutrition needs following a diagnosis is essential to maximizing physical and cognitive capacity as well as supporting quality of life.

How Dementia impacts eating:

Accessing, recognising, preparing and eating food safely relies on complex brain processing which is impacted by dementia.

The nutrition needed to fuel and protect the body and brain, fight illness and infections and maintain good physical health doesn't change. Therefore, carers and family members have a vital role to play in assisting a person living with dementia to eat well, despite any cognitive challenges they might face.

**Nutrition and Dementia report by Alzheimer's Disease International, 2014.*

Understanding that some of the following can occur due to dementia can help with meal preparation, planning and nutrition:

- Often a person with dementia either won't feel hungry, or is unable to express hunger adequately. Food refusal or not eating the food provided should not always be taken to mean *'I'm not hungry'*. Instead other steps need to be taken to ensure the individual is eating enough during the day.
- Sometimes food is not recognised, this can be because of the dementia, or due to modern interpretations of meals, drinks and snacks which present food in new ways. Individuals who tend to reminisce about the past may find some food unrecognisable and not enticing. Make sure foods look appealing and recognisable when serving meals.
- The complex planning involved in purchasing, transporting, storing, preparing and cooking foods, as well as serving meals, and eating can be impacted by dementia. An incorrect step or the wrong ingredients can unfortunately lead to a missed eating opportunity.
- Confusion about how to eat may be experienced by someone living with dementia. Even when food has been prepared by someone else, cutlery may not be recognised or the brain signal to start eating is absent or delayed, causing confusion around the meal.
- Individuals who are distracted by TV or other activity in the dining area may lose interest in eating or miss a meal altogether.
- Swallowing issues are very common with dementia and as a result changes to the texture of food and drinks may be prescribed by a speech pathologist. Unfortunately, food modifications can eliminate some regularly enjoyed meals and this can often result in more food being refused and/or inadequate amounts eaten.

It is vital for a person with dementia to never miss an opportunity for nourishment and the pleasure of food. That can mean thinking 'outside the box' to find solutions to support them with their nutritional needs.





Some suggestions to help combat food refusal are:

- Even if hunger is not expressed or is denied, continue to offer light meals, snacks and drinks at the usual time. Indicate that now it is time to eat or drink and provide accordingly.
- When presenting food or drink, offer encouragement and a simple description.
- Sit and share food and drinks so that eating can be mimicked.
- Offer foods that can be eaten with the fingers, especially for those who don't like to sit for a long time. Eating with our hands is our earliest food experience. Ice cream cones, cubes of cheese, baked treats, carrots & celery sticks, party pies, mini quiches and hot chips are good alternatives, and can also bring joy as well as nutrition to a person with dementia.
- Ensuring food contrasts well on the plate can assist those with visual disturbances. Light coloured foods on darker plates, darker foods on light coloured crockery may help.
- Minimise distraction in dining areas and ensure the room is set up properly to look like it's mealtime. Where possible, prepare and cook food to help tap into the persons memory of eating.

It is common for people living with dementia to develop preferences for sweeter or more salty foods than they previously had, to often choose unusual taste combinations or eat the same food at every meal. Fortifying preferred foods with nutritional powders, milk, other protein powders or ground nuts can help to boost nutrition.

Dehydration is a significant issue in dementia, and can often attribute to confusion. Every cup of water, tea or other drink matters. Regularly offer a variety of drinks to ensure hydration is maintained.





NEED MORE HELP?

Here are some organisations and services that can assist you:

Dementia Australia represent the 472,000 Australians living with dementia and the almost 1.6 million Australians involved in their care.

They advocate for the needs of people living with all types of dementia, and for their families and carers, and provide support services, education and information.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of Dementia and Alzheimer's Associations around the world.

They are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

For more information visit dementia.org.au or call 1800 100 500

The Dementia Behaviour Management Advisory Service (DBMAS) provides clinical support for people caring for someone with dementia who is demonstrating behavioural and psychological symptoms of dementia (BPSD) which are impacting on their care.

The DBMAS provides:

- Assessment of the person with dementia
- Clinical support, information and advice (either face to face, telephone/ tele-health or email)
- Care planning, case conferences and short term case management
- Mentoring for care providers and clinical supervision
- Education and training for care providers.

Call 1800 699 799

The Wicking Dementia Research and Education Centre (WDREC) through the University of Tasmania is unique in Australia as an integrated dementia centre that is active across a range of disciplines, seeking to improve the lives of people with dementia and their carers. The WDREC aims to:

- Better understand the diseases affecting the brain that cause progressive decline in functioning affecting memory, problem solving skills, function and social behaviour;
- Develop evidence-based models of care provision for people with dementia and their carers;
- Explore the trajectory of brain and functional changes in ageing through dementia;
- Provide educational programs to build knowledge and understanding of dementia within the community.

For more research information visit utas.edu.au/wicking/research

Dementia Centre For Research Collaboration has several programs of activity aimed at improving quality of life for people living with dementia, and supporting home based carers.

Free resource topics include; Living with dementia, professional care/services, diagnosis & planning care, prevention lifestyle, risk and education & training.

For more information visit dementiaresearch.org.au

National Dementia Helpline is a free confidential phone and email information and support service which provides:

- Information about dementia and memory loss
- Information on how you may be able to reduce the risk of getting dementia
- Information about government support services (including My Aged Care, the Carer Gateway, Centrelink)
- Information about services in your area
- Emotional support to help you manage the impact of dementia.

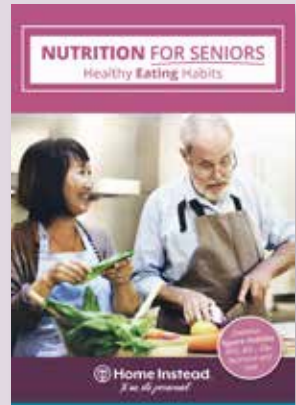
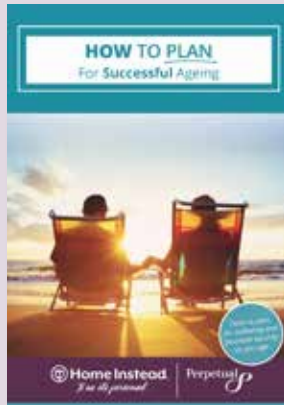
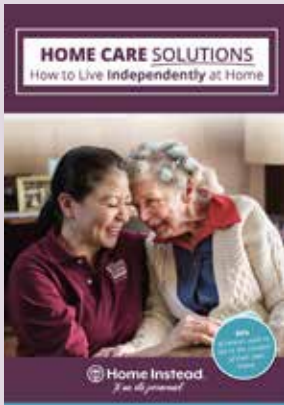
Call 1800 100 500

Home Instead Resources

Information, tools, tips and other guides.

As a community care organisation, we are committed to educating and empowering individuals, families, carers and communities with an understanding of the various home care services and support available to them.

Home Instead strives to help you navigate ageing with a variety of senior care resources. From help with understanding the aged care system, negotiating family relationships and difficult conversations to resources on home safety, end-of-life planning and managing conditions such as dementia; helping you find answers is important to us.



Our website is another great resource for senior focused information along with our monthly newsletter and Facebook pages.

Find out more today at HomeInstead.com.au

I would **recommend** Home Instead services to anyone looking for **personalised, kind, and respectful** care for their loved ones

Maureen



To us, it's personal.

Home Instead is **YOUR** specialist, national provider of high quality in-home care for ageing adults.

We help with a range of personal and lifestyle needs while providing welcome companionship. Our services include assistance with personal care, light household duties, meal preparation, medication reminders, transport to appointments, shopping and social outings. We take personal responsibility for providing the best in-home care and support to meet our clients' needs and are committed to addressing the individual and national challenges of Australia's ageing population. Established in 1994, Home Instead now provides senior care across a network of over 1200 offices around the world.

In Australia, at Home Instead our national network of independently owned and operated offices are committed to changing the face of ageing by enhancing the lives of ageing adults and their families.

We understand that to you, it's about finding trustworthy care for your ageing loved one.

To us, it's personal.

Contact your local Home Instead office for a free no-obligation care consultation where we can discuss your needs and provide you with information, advice, care and support to help you and your family find the right home care solution for you.

 **Home Instead.**
To us, it's personal

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