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THE DIBA

The official newsletter of The Dementia Inclusive Ballina Alliance



THE DEMENTIA INCLUSIVE BALLINA ALLIANCE IS AN INCORPORATED NOT FOR PROFIT COMMUNITY ORGANISATION. WE STRIVE TO WORK WITH THE COMMUNITY TO TAKE ACTION TO IMPROVE THE LIVES OF PEOPLE LIVING WITH DEMENTIA AND THEIR CARERS.

> dementiainclusiveballina@gmail.com Mel 0409 810 735

> > www.dib.org.au

DEMENTIA INCLUSIVE BALLINA ACKNOWLEDGES THE TRADITIONAL CUSTODIANS OF THE LAND ON WHICH WE LIVE AND CARE AND PAYS RESPECT TO THE ELDERS PAST, PRESENT AND EMERGING



IN THIS EDITION

FEATURE ARTICLE - WHAT IS 'SUNDOWNING' AND WHY DOES IT HAPPEN TO MANY PEOPLE WITH DEMENTIA

UPCOMING EVENTS - 2023

WEDNESDAY ACTIVITY GROUP 10:30AM - 12:30PM THE BALLINA AEROCLUB

10AM-12PM CAFE SEBASTIAN 2ND MONDAY MONTH 2023 14TH AUGUST, 11TH SEPT, 9TH OCT, 13TH NOV, 11TH DEC

DIGITAL LITERACY TRAINING ENROLLING NOW

DEMENTIA SYMPOSIUM FRI 22ND & SAT 23RD SEPT



WHAT IS 'SUNDOWNING' AND WHY DOES IT HAPPEN TO MANY PEOPLE WITH **DEMENTIA?**

Steve Macfarlane, Head of Clinical Services, Dementia Support Australia, & Associate Professor of Psychiatry, Monash University

The term "sundowning" is sometimes used to describe a tendency for people living with dementia to become more confused in the late afternoon and into the night.

At the outset, I should emphasise the term "sundowning" is overly simplistic, as it's a shorthand term that can encompass a vast number of behaviours in many different contexts. When assessing changed behaviours in dementia, it's always better to hear a full and accurate description of what the person is actually doing at these times, rather than to just accept that "they're sundowning."

This set of behaviours commonly described as "sundowning" often includes (but is not limited to) confusion, anxiety, agitation, pacing and "shadowing" others. It may look different depending on the stage of dementia, the person's personality and past behaviour patterns, and the presence of specific triggers.

Why then, do such altered behaviours tend to happen at specific times of the day? And what should you do when it happens to your loved one?

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Fading light

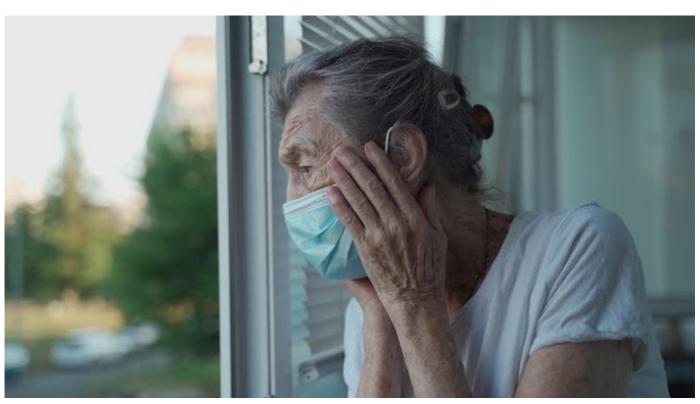
We all interpret the world via the information that enters our brains through our five senses. Chief among these are sight and sound.

Imagine the difficulty you'd have if asked to perform a complex task while in a darkened room.

People living with dementia are just as dependent on sensory input to make sense of and correctly interpret their environment.

As <u>light fades</u> towards the end of the day, so too does the amount of sensory input available to help a dementia patient interpret the world.

The <u>impact</u> of this on a brain struggling to integrate sensory information at the best of times can be significant, resulting in increased confusion and unexpected behaviours.



Cognitive exhaustion

We have all heard it said that we only use a fraction our brain power, and it is true we all have far more brain power than we typically require for most of the day's mundane tasks.

This "cognitive reserve" can be brought to bear when we are faced with complex or stressful tasks that require more mental effort. But what if you just don't have much cognitive reserve?

The changes that ultimately lead to symptoms of Alzheimer's disease can begin to develop for as many as $\underline{30 \text{ years}}$ before the onset of symptoms.

During that time, in simple terms, the condition eats away at our cognitive reserve.

It is only when the damage done is so significant our brains can no longer compensate for it that we develop the first symptoms of Alzheimer's disease and other dementias.

So by the time someone first presents with very early dementia symptoms, a lot of damage has already been done. Cognitive reserve has been lost, and the symptoms of memory loss finally become apparent.

As a result, people living with dementia are required to exert far more mental effort during the course of a routine day than most of us.

We have all felt cognitively exhausted, run down and perhaps somewhat irritable after a long day doing a difficult task that has consumed an extreme amount of mental effort just to get through their daytime routine.

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So is it any surprise that after several hours of concerted mental effort just to get by (often in an unfamiliar place), people tend to get <u>cognitively exhausted</u>?

What should I do if it happens to my loved one?

The homes of people living with dementia should be <u>well-lit</u> in the late afternoons and evenings when the sun is going down to help the person with dementia integrate and interpret sensory input.

A <u>short nap</u> after lunch may help alleviate cognitive fatigue towards the end of the day. It gives the brain, and along with it a person's resilience, an opportunity to "recharge".

However, there is no substitute for a fuller assessment of the other causes that might contribute to altered behaviour.



<u>Unmet needs</u> such as hunger or thirst, the presence of pain, depression, boredom or loneliness can all contribute, as can stimulants such as caffeine or sugar being given too late in the day. The behaviours too often described by the overly simplistic term "sundowning" are complex and their causes are often highly individual and interrelated. As is often the case in medicine, a particular set of symptoms is often best managed by better understanding the root causes.

REIMAGINING LIFE WITH DEMENTIA PROGRAM

5-day retreat

For people in the early stages of dementia and their support person

The 5-day retreat will give people living with dementia and their support partner hope beyond their diagnosis fostering a sense of optimism and possibilities for a brighter future.

Group Homes Australia welcomes you to a 5-day, live-in retreat designed specifically for people living with dementia. The program, which accommodates five people and their support partners, provides innovative dementia education, shares tools and strategies to help you live well, and the opportunity to connect with others in a supportive and caring environment at the retreat and into the future.

Accommodation, food and all retreat inclusions are at no cost to participants.

This service is funded by the Australian Government and led by Group Homes Australia.

Topics include:

- · Understanding dementia
- · Strategies and tools for living well
- · Creating cognitive ramps
- Human needs and how they can be impacted by dementia
- · Communicating well
- Sexuality and intimacy
- · Self-care
- · Finding purpose and meaning
- · Sleep, food and mood
- · Your environment
- · Community support
- · Assistive technology
- Planning for the future
- · Movement and meditation



If you have any questions or would like to find out more, contact **Donna Ward** at dward@grouphomes.com.au.

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CHAIR - Anne Moehead



Welcome to our winter edition of the Dementia Inclusive Ballina Alliance newsletter. I hope all our readers are keeping warm and avoiding the many challenging 'bugs' floating in the air trying to infect us and inflict us with their symptoms. Stay well.

On behalf of the DIBA committee we continue to work hard attracting sponsorship, donations, and grants to assist us to achieve our goal of promoting the inclusion of people living with dementia and their carers within the local community to enable enjoyment and the best quality of life possible.

Plans are underway to deliver our annual Dementia Awareness Week symposium. Future Fit our Dementia Community; lessons learnt from recent events, which this year will be a two-day event, Friday 22nd and Saturday 23rd September. See more details in "Watch this Space". Registrations are open.

The committee has delivered several information sessions to local services. Our aim in undertaking these presentations is to increase our voice locally on behalf of our members and to be recognised as a point of contact if our community is seeking advice, local resources, or information regarding dementia.

The committee has recognised the need to review the services and supports available for people with early onset dementia. Dr Sabrina Pit, our grants coordinator has been successful in gaining a small grant on our behalf with the aim of developing a Well-being program focussing on maintaining activities of daily living skills and building life skills, confidence, and social inclusion. This is an exciting new venture for us so watch this space and contact us if you would like to be involved.

On behalf of our busy and dedicated committee it is a privilege to work towards making a difference for you, our members. We thank you.

WEDNESDAY ACTIVITY UPDATE - Meg Pickup

The weekly meetings are valued by people who attend. They especially appreciate gathering in a welcoming and non-judgemental environment where people with similar experiences can meet and interact.

People appreciate the variety of activities. We held another successful BBQ at Missingham Park with Ballina-on-Richmond Rotary cooking up a treat. While there we were entertained by Aboriginal students from Ballina Public School who were being filmed dancing and singing. Scone making was a hit. We were able to enjoy the end product as part of morning tea. We made enough for everyone to take home some to enjoy later. One activity that is ongoing is a mural of the local area. The choir singing is still enjoyed as are the musical performances. Participants are encouraged to suggest activities than can be included in the program.

The group has evolved, and we had decided that our motto is "Live, love, laugh and be happy."; a line from the Red, Red, Robyn song we sing as part of our choir group.

We continue to meet from 10:30pm-12:30pm at the Ballina Aero Club, located at the Ballina Byron Gateway Airport, off Southern Cross Drive near the Ballina Community Recycling Centre. Alliance members pay \$5 and non-members \$7 for morning tea. You can become a member of DIB, which costs \$5, the first time you attend. Just turn up and spend enjoyable time with others, who have similar experiences to you. Roadside parking is available close to the venue.

Again, a big thank you to the volunteers without whose support the activity group would not exist and the participants who help make the activity group a rewarding experience for all who attend.

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DIGITAL LITERACY TRAINING OFFICER - Susan Burgess



The "Be Connected" Digital Literacy Program that we organised through grant funding was finalised in late April. The aim of this program was to reach out to those people who feel impacted by the fast pace of the digital world. Our training approached the basics of using the internet and enabled those who participated to be able to keep up with technology as it changes as well as being aware of how to determine if an email is "scam mail". The "Be Connected" website is a wealth of up-to-date information for seniors and free to join.

https://beconnected.esafety.gov.au/

ADVISORY GROUP CHAIR - Gwen Mapstone

Another three months has quickly passed attending monthly meetings of DIBA committee meetings via Zoom and our weekly DIB Activity Group.

It is exciting to see grants approved and some new sponsors to assist our programs that the Advisory group have suggested to the Committee.

Attendance at our weekly meetings at the Ballina Aero Club have increased with regular participation.

Easter Hat Parade and Easter eggs galore. Remembering ANZAC Day making Anzac Biscuits which was enjoyed by all. Our group playing drums together in the drumming session lead by Susan.

An alternative day out was a BBQ at Missingham Park which was assisted by the Ballina-on-Richmond Rotary Club cooking the sausages. Weather was fabulous and an impromptu entertainment of Aboriginal Students who were at the park making a video made it even more special. Several folk walked around the paths by the river.

Joan and Peter provide an entertaining musical program, stunning songs and everyone joining in for a great singing session.

Scone making day had the best aroma in the room and delicious taste. Lots of scones went home with the makers. Thank you Valda for manning the oven and to the other volunteers doing the preparation, and Meg excelled with the shopping for the ingredients.

A new activity is a joint Mural for each person to help with artwork, drawings, adding decorative items and ideas. This will be worked on over several intervals. As you have read, we have had lots planned and there is more to come over the next 3 months.

Give this a thought; Time and Friends are two things that become more valuable the older we get.

ANNIVERSARY CELEBRATION - Wednesday Activity Group



On Wednesday 5th July the DIB Activity group celebrated our First Birthday. This was an exciting day and enjoyed by all those present. We were honoured to have three government representatives, Justine Elliot, the Federal Member for Richmond; Tamara Smith, the State Member for Ballina; and Cr. Sharon Cadwallader Ballina's Mayor. they all expressed their heartfelt congratulations on the success of the DIB activity program. After a mouth-watering morning tea, Helen Jarvis entertained us all. A big thanks to all who have assisted us over the past twelve months.

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WATCH THIS SPACE

Dementia Symposium Register Now

Future Fit our Dementia Community Lessons learnt from recent events

Day 1: Friday 22nd September

For people living with dementia, their carers

and interested community members.

Day 2: Saturday 23rd September

For professionals working in the field and





Register here

Digital Literacy Training Enrolling Now!

We are putting a waitlist together of people that are interested in learning new or more skills about using mobile phones and computers, including cyber security, telehealth and much, much more. We will offer free sessions in the months ahead. All levels are welcome.

Registration:

dementiainclusiveballina@gmail.com or phone Sabrina Pitt on 0429 455 720

Art workshops

Date: Wednesday 23rd and 30th August

Time: 10:30am - 12:00pm Where: Ballina Aeroclub

Cost: \$15 (includes morning tea and materials)
People living with dementia and carers are
invited to art workshops to produce artwork

for the 2024 calendar.

Fund raising Bunnings BBQ

Date: Saturday 16th September <u>Time: From 8:30am</u> - 4:30pm

Where: Ballina Bunnings Warehouse

Supported by Home Instead.

Money raised will be donated to The Dementia Inclusive Ballina Alliance. Helpers needed.

Carers Week Luncheon

Date: Friday 19th October Time: 11am - 1:30pm Where: Ballina Aeroclub

A free luncheon for carers of people living with dementia and people living with dementia.

More information to follow.

MEMBERS SAY









Thank you for the time I was here. Most enjoyable. Keep it up. (Billie)

Nice. Meet new and friendly people. (Anon)

Lots of laughter and chatter today. (N & G)

Thanks for all the goodies and friendship. Happy Easter to all. (Brian and Julie)

What a great day we have had. Thank you to everyone for giving us a wonderful time. (Anon)

Thank you for another great day. God willing, we will meet again next Wednesday. (Dick & Judy)

Thanks for such a wonderful day. We have enjoyed it all. Thank you so much for our outdoor get together, plus our wonderful lunch. (Anon)

Thanks for another lovely time. It's becoming the highlight of our week. (P & J Dillema)

Thought today was a bit ambitious (making Anzac biscuits), but it went swimmingly and the girl's "pulled it off". (Carolyn)

Today's singing was great, finished off with Robin's 'Over the Rainbow'. She is a surprise package XXX. (Judy)

Today drawing and games tested the art side of the brain, but lots of laughing could be heard. (Judy)

The day is not long enough - longer please. (Robin)

Scone making well organised and delicious. (Gwen)

Terrific output. Well done organisers. (Anon)

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CAFE SEBASTIAN
BALLINA FAIR SHOPPING CENTRE

Dementia Cafe For people living with dementia and their carers

A safe space for people to come together and make new connection:

When: 2nd Monday of the month (There will be no April Cafe due to Public Holida; 8th May, 12th June, 10th July, 14th Aug, 11th Sept, 9th Oct, 13th Nov, 11th Dec Time: 10am - 12pm

Where: Cafe Sebastian Ballina Fair Shopping Centre















Health Northern NSW Local Health District





FUTURE FIT OUR DEMENTIA

COMMUNITY

Lessons learnt from recent events

2 Day Symposium

Or via QR code below





Calendar 2023 WEDNESDAYS, BALLINA AEROCLUB

10:30AM - 12:30PM

2nd August Drumming

9th August Life story telling

16th August Music and singing with Joan & Peter

23rd August Art Program - 2024 Calendar

30th August Art Program - 2024 Calendar

6th Spetember Baking slices

13th September Art & Craftworks

20th September Music and singing with Joan & Peter

7th September Sharing: - Bring a special item or photo

4th October Special Guest Performer

11th October Games & Activities

18th October Music and singing with Joan & Peter

25th October Art & Craftworks

1st November Melbourne Cup - Hat parade & Trivia

8th November BBQ Missingham Park - Walk & Games

15th November Music and singing with Joan & Peter

22nd November Drumming

29th November Ball Games

6th December Christmas Card Making Activity

th December Christmas Cooking 20th December Christmas Party Celebrations

NEED SUPPORT

MY AGED CARE

Information and access to aged care services 1800 200 422

www.myagedcare.gov.au

THE CARER GATEWAY

Information about emergency respite and caer support 1800 422 737

THE DEMENTIA OUTREACH SERVICE

Dementia advice and support **Ballina Community Health** 02 6620 6274

CARERS NSW

Information for carers 02 9280 4744

DEMENTIA AUSTRALIA 24 HOUR HELPLINE

1800 100 500

www.dementia.org.au

FORWARD WITH DEMENTIA

Information for people living with dementia, carers and health professionals www.forwardwithdementia.au

NSW ELDER ABUSE HELPLINE

1300 651 192

www.eapu.com.au

BYRON SHIRE RESPITE CARERS COFFEE CLUB

Support group for carers Emma White - 02 6685 1629



BEATING HEARTS OF LISMORE

Is a FREE, volunteer led, weekly social gathering for older people living in

Where: Lismore Heights Sports, Recreation and Community Club High Street, Lismore Heights (downstairs, enter from carpark)

When: Mondays (excluding school and public holidays)

Time: 10-11.30am