

Alzheimer's South Africa NPC Eastern Cape Region



Quarterly Newsletter September 2021

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A Message from the Regional Manager

It is somewhat difficult to start this Newsletter with anything profound. The COVID-19 pandemic continues to dominate, dictate and curtail our lives and most definitely the services offered by Alzheimer's Eastern Cape. We continue to dig deep, adapt and respond so that we may remain supportive to those living with dementia and their families.

We are very aware of the enormous stress our clients are experiencing - some are caring for loved ones and battling because financial constraints prevent them from opting for a care facility; some are having to have a carer in the family space and would prefer a care home but circumstances prevent this option too; some have loved ones in care facilities and are unable to see them due to restrictions; and some have lost loved ones who were in care facilities and due to restriction, could sadly not be with them in their final hours. Many loved ones live far away and cannot make visits, ever aware that their connection, due to fading memory, is becoming weaker. Supporting a loved one who is trying to remain patient with a family member suffering from dementia, who continually repeats themselves or perhaps hides essential items like keys is understandably a massive challenge. These are just some of the realities of the pandemic we are faced with when providing services.

World Alzheimer's Day has come and gone, and our coordinated efforts nationally seem to have been better than ever before. ASA Free State appeared on SABC2. ASA had various slots on different Radio Stations, and a Journal article written by Heather was published in a medical periodical, to name but a few highlights. ASA EC Region presented two virtual Talks on 22 September.



A Message from the Regional Manager

Our dear local carer, Eunice Dumezweni, represented ASA in Lady Frere where the MEC Social Development held an event to raise awareness of the plight of the elderly living with dementia after cases of severe abuse have come to light in that region recently. Eunice used the opportunity to raise awareness about dementia and also distributed our Xhosa brochures at the event.

Fundraising opportunities remain limited in the current economic climate. However, we are grateful to those folk who are able to make a donation towards our clinic services.

We remain especially indebted to the Ezethu Development Trust for their enormous contribution to our work in the Nelson Mandela Bay Metro. The Trust has been both insightful and graciously understanding of our need to adapt services and opt for a slightly slower pace at times.

Our Region says a big Thank You to Marie Lubbe who retires as the Bookkeeper. We extend a very warm Welcome to Jenny Ah Chong who takes over from Marie. We wish Jenny a long and happy stay with us.

ASA Eastern Cape Region continues to render an adapted but comprehensive service to those living with various forms of dementia as well as their family members. We also continue to provide Dementia Care training for caregivers. Please don't hesitate to contact us for further information.

Sincerely,
Heather



World Alzheimer's Day 2021

To commemorate World Alzheimer's Day, **Santa van Rooyen**, a Social Worker by profession presented a virtual Talk on **Dementia Behaviour**.

Santa explained how the behaviour and personality of a person living with dementia is likely to change over time and how this can become frustrating for the person living with dementia and the people around them.

Traditionally, in dementia-care the terms "aggressive", "difficult" and "challenging" were often used to describe this changing behaviour. A person living with dementia was often labelled as "the aggressive resident" or "the demented person".

Santa informed her audience about the new focus on "**person-centred care**" and the important shift away from labelling the individual to searching for the meaning or reason underlying the person's behaviour.

She clarified how behaviour is a form of non-verbal communication and when the thinking, memory and reasoning part of a person with dementia's brain becomes increasingly impaired as the disease progresses, this becomes the only means of communication available to them. People living with dementia need a way to communicate their pain, fear, confusion, feeling threatened, loneliness and discomfort.

Santa advised her audience - when dealing with changing behaviours displayed by a person living with dementia, it is important to remember that the person is not being deliberately difficult or vindictive. A person living with dementia has a sense of reality which may be quite different from ours, however it is still very real. She further advised her audience members to consistently remind themselves that a person living with dementia cannot remember.

Santa reminded her audience that people living with dementia still need engagement and human connection and therefore it is important to be sensitive to their emotions and feelings and to try hard to understand their feelings and the underlying reasons for their changed behaviour.

WORLD ALZHEIMER'S DAY

50 SHADES OF DEMENTIA BEHAVIOUR

A TALK BY
SANTA VAN ROOYEN
(SOCIAL WORKER)
WED, 22 SEPTEMBER 2021
10 A.M. - 1 HOUR INCL. Q&A

JOIN US VIA ZOOM



Santa stressed that while we can't change the person living with dementia, we can change our responses to their behaviour. She reminded all that dementia or associated behaviour does not define the person and that the person is still the same individual they've always been. It is only the resultant behaviour that has changed.

She furthermore presented two types of behaviours:

Responsive Behaviour

Responsive Behaviour is the actions, words or gestures a person with dementia uses to communicate something negative, frustrating or confusing in their social and physical environment. All behaviour (response) is the non-verbal communication of meanings, needs and concerns. Try to determine the reason for the behaviour as understanding the behaviour will help you to change your approach to support the person living with dementia.

Re-active Behaviour

Reactive behaviour refers to "acting out", usually in hostile and reactive ways. This behaviour is often an extreme way of expressing feelings of resentment, anger, discomfort, or frustration. As the communication skills of the person decrease, they may use physical behaviours such as kicking or hitting to express how they are feeling.

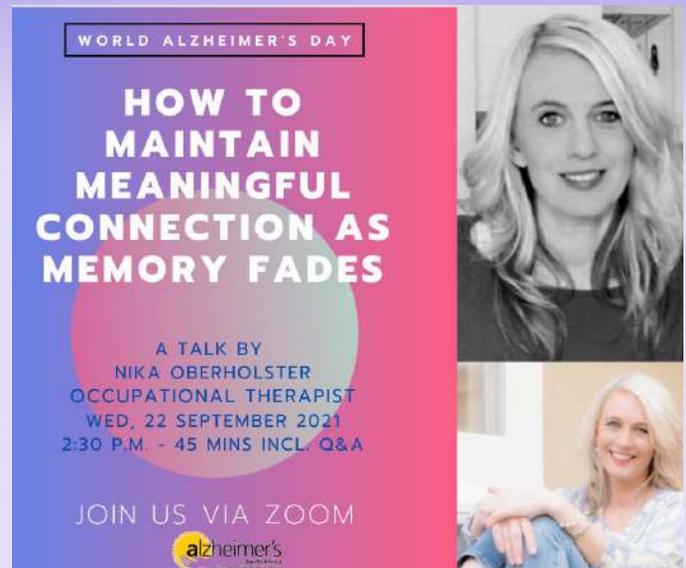
Reactive or hostile behaviour may happen at any stage of dementia, but it typically occurs during the middle to late stages of the illness. Whenever you encounter reactive behaviour, it is important to look beyond the behaviour and identify possible causes and consequences, nature, duration, and the circumstances surrounding the behaviour.

You need to have realistic expectations and control your responses and anger towards the person living with dementia. It is up to you to turn around and walk away when being verbally abused or physically attacked. The person is not trying to deliberately provoke you or be difficult or vindictive but rather trying to communicate a need or feeling.

World Alzheimer's Day 2021

On how best to handle behaviours, Santa advised that the person with dementia cannot tell you about their physical discomfort (infection, pain, on-going constipation, urinary incontinence discomfort) or psychological disorders (depression, anxiety). She encouraged all to search for the reason for the change in behaviour and to look past the person's behaviour and to instead focus on their feelings. Santa further advised that our approach to the different behaviours should be one of "supportive intervention" - to consider the person with dementia's personality, to know their history, to consider their present environment and to get to know who the people are in their life. She advised to keep detailed notes of their changed behaviour, to identify the triggers and patterns for their behaviour and to encourage the involvement of their family members, friends and the multi-professional team members throughout the process. This enables one to draw up a Behaviour Profile to better understand the changed behaviour of the person living with dementia. It is important to forgive oneself for perhaps failing to respond appropriately. Santa ended off with a reminder that there are no hard-and-fast rules or a "one size fits all" approach.

Later in the day, **Nika Oberholster**, an **Occupational Therapist** by profession delivered her virtual presentation. Nika's Talk addressed the importance of **"maintaining meaningful relationships as memory begins to fade"**. Nika reminded her audience that dementia can affect each individual differently and therefore it is not possible to make assumptions or to generalise how to navigate the journey with a loved one. Each couple's journey is completely unique to them, furthermore it changes constantly. However, there are certain issues that commonly arise when a partner develops dementia. The first step is to become aware of all the possible challenges one can expect. Nika cautioned - "if you've met one person with dementia, you've only met one". Each person is different with unique needs. Caregivers could help meet the needs of the person living with dementia by getting to know the person, their personal likes and dislikes and to understand the level of engagement activity the person can cope with.



Nika explained that sensory stimulation and meaningful engagement is not always a "planned" activity but can form part of every interaction with the person living with dementia. "Fancy" activity plans are not necessary. It is instead more helpful to observe the person and their behaviour in order to understand what they are expressing in terms of their sensory and other needs.

Nika pointed out that as a partner or child of the person living with dementia, the focus should ideally be on "quality of life" rather than "treatment of a condition".

She reminded her audience of the importance of seeking support from family, friends or Support Groups and to prioritise one's own mental and physical health as well. She emphasised that self-care is not selfish and encouraged us to be wise and seek professional help if one is struggling to cope.

A Tribute to a dear Colleague

It was so devastating to hear of the brutal murder of our dear Sr Flo. Her death was so untimely and cruel. Sr Flo meant more to ASA EC than we can ever put in words.

Sr Flo was always just a phone call away. She was a wealth of knowledge and experience when it came to Aged Care generally and Dementia Care specifically.

The Support Group facilitated by Sr Flo was an invaluable resource for families struggling with the challenges of caring for a loved one with dementia.

We are sure that Sr Flo would want us to pick up the pieces and move on with this form of service and we shall try to do so in her memory.

Sr Flo will also be remembered for her enthusiastic involvement in the Annual Garden Tour, a fundraiser for ASA's EC Region, held in East London. The money raised assisted with our awareness raising work and clinic services.

Update on Regional Activities

Training update

Dementia Trainer, **Sr Linda Swartz** reports that five groups of community-based and institutionally-based caregivers have undergone training in Dementia Care.

The PEDI Development Community Project and the Motherwell Homecare Community Project delegated 12 carers each to attend the course offered in May and June.

Echo Foundation Aged Care Services sent ten carers to attend the course and Likusasa Lomama Community Project had 22 carers participate in the course held in September.

The duration of the Dementia Care course is four days and is spread over a 4-week period. Please enquire with Dr Heather Rauch should you wish to attend our short courses.

Ezethu-funded Projects update

The roll-out of the projects has been a little slower than planned due to the pandemic. Care facilities are really stretched and don't seem to have the capacity for anything more than absolute essentials. Even attending online training is a challenge for care facilities.

However, we have done training where we can and we continue to reach out to care homes and offer our services. We recently trained carers based at Echo Foundation and also The Nightingale Trust.

We have again been resourceful and adapted the projects slightly by rendering our services to small groups or even one-on-one training – as this has been safe, manageable and very much needed in crisis situations.

Clinic update

Sadly, our clinics are not yet able to meet. We are being extra cautious on the one hand as our clients are those suffering from various forms of dementia, are mostly elderly and some reside in care facilities. Our clients are especially vulnerable.

Venues for our clinics and Support Group meetings have not been accessible due to COVID-19 restrictions, however, please don't let scripts lapse as we can make arrangements with our clinic team members.

It is so important to make mention of **Sr Linda Swartz** who has been of great help, conducting home visits with Dr Heather Rauch in an effort to ensure that we meet the needs of the families we serve.

All new referrals and existing clients still receive clinical services individually. We can still be effective in these "pandemic times" - sometimes it might just take a little longer and although there might be a hoop or two to jump through it is not impossible.

Support Groups update

While Support Groups are not meeting regularly, the Support Group Leaders remain unwavering in their commitment to support families on an individual basis. Leaders are available to assist with referrals to relevant resources. Should you have any need, please contact the Support Group Leader in your area.

Trainer: Sr. Linda Swartz



An Article written by Dr Heather Rauch for The South African Association for Social Workers in Private Practice

DEMENTIA – A ‘FAMILY’ ILLNESS, WITH A FAR-REACHING IMPACT

Tuesday, 21 September is World Alzheimer’s Day – a day in which organisations around the world focus their efforts on raising awareness for Alzheimer’s and dementia. “Every three seconds, someone in the world develops dementia,” says Dr Heather Rauch, a clinical social worker with her doctorate in social work, and member of [SAASWIPP](#) (South African Association for Social Workers in Private Practice). The WHO Global status report 2021 indicates that as many as 139 million people could be suffering from dementia by 2050 (an increase from 55 million in 2019).

Alzheimer’s, the most common form of dementia, is a general term for memory loss and the impairment of other intellectual abilities that are serious enough to interfere with daily life. It accounts for 50 to 80 percent of dementia cases.

Rauch explains that dementia affects the structure and chemistry of the brain that is responsible for day-to-day functioning, communication, thinking and planning: “Dementia is a term used to describe a group of symptoms caused by different disorders and conditions that leads to the deterioration of a person’s ability to remember, communicate or make decisions”. Whilst the exact cause of the disease is unknown, it is known to be both progressive and incurable. “Over time, the brain will continue to deteriorate, impacting the person’s daily performance until they are no longer able to function and lose the ability to lead a normal life,” says Rauch.

Although certain prescribed medications can slow the progression, this is only possible for a certain length of time. “It is actually very difficult to get an exact and final diagnosis, with a true diagnosis only possible after a post-mortem has been conducted,” continues Rauch. Early diagnosis is usually made clinically (presenting facts) rather than medically (tests).

The first step in a clinical diagnosis will usually entail ruling out any other diseases (constipation, UTI, temperature, pneumonia, very low blood pressure, dehydration, stroke, low folic acid levels, lack of vitamins, brain tumour, stress, trauma) as a probable cause for the symptoms being experienced.

Certain symptoms exhibited in the early stages of the disease could also look similar to the natural aging process.



“It is a difficult and complex process and it is highly recommended to involve a specialist such as a psychiatrist or neurologist,” advises Rauch. The family also have a very important role to play in the diagnosis as they know both present and past information about the person.

While signs and symptoms of Alzheimer’s differ from person to person, Alzheimer’s is usually characterised by four stages: mild, moderate, severe and terminal.

Mild: Symptoms begin slowly and are usually mild and can be hidden. This is why most people are not diagnosed until the moderate stage. Loss of short-term memory is usually one of the most common symptoms in this stage.

Moderate: The person is often aware that something is wrong and may ask for help. In this stage, the patient may need more help and frequent reminders to help them cope with daily living. The person may also become very upset or angry and aggressive as they may feel frustrated that they are not able to do things for themselves as they did before.

Severe: At this stage, people are not aware of their memory changes and usually cannot complete even simple or routine tasks and will become increasingly frail.

Terminal: Often at this stage, the patient requires constant care. Communication is minimal and often non-existent. The person is unable to help him or herself even in the smallest way. Some people never reach this stage.

Rauch outlines some of the things that can be done in order to help a person suffering from dementia. These include:

Stick to a regular daily routine. Make sure there are lots of familiar objects around to be seen and enjoyed.

Regularly check on the patient’s safety.

Make sure the patient eats well and drinks plenty of fluids.

Help the patient remain as independent as possible for as long as possible.

Provide for regular exercise and recreation.

Keep in touch with friends and family.

Use written memory aids such as large calendars and clocks, written lists of daily routines, reminders about safety measures and name tags placed on important objects.

Ensure that the patient gets regular medical check-ups.

Plan for future needs such as respite care or nursing home placement.

Provide lots of emotional support to the patient and all the caregivers.

If medicines are prescribed, see that the patient takes them regularly.

Join a support group of other people who care for people with dementia.

Ask for help with money problems, legal problems, day to day advice, emotional issues, respite care or nursing home placement when they are needed.

Check the home for safety features such as bars on the wall near the toilet and bathtub, night lights in hallways and on the stairs, non-slip rugs, lowering the height of the bed to prevent falls, lowering the temperature of the geyser water, putting bells on all external doors so that you can hear if the patient is going outside, etc.

Make sure all health care providers have a complete list of all the patient’s prescription and over the counter medicines.

If incontinence is a problem, remind the patient to use the toilet every two hours.

Enrol the patient in a dementia day programme to provide stimulation for the patient respite for the caregiver.

“Alzheimer’s, and dementia in general, can be an incredibly difficult and emotionally distressing experience particularly for the patient’s loved ones and family members,” says Rauch. Often known as a ‘family disease’, dementia not only affects the patient but has an enormous impact on their family and friends as well. A patient, particularly in the more advanced stages of the illness, may not actually be aware of how ill they are. There is a kindness in this. However, the patient’s reality can often be very different from the reality of their family and loved ones.

“The family of the patient are acutely aware of, and witness to, the gradual deterioration of their loved one,” empathises Rauch. It can take as long as 10 to 15 years from initial diagnosis until the eventual passing of the patient, with the last five years often seeing the patient admitted to an old age home or care facility.

“This is an extraordinarily long and cruel grieving process during which time family members may experience a range of emotions from loss and grief through to guilt, anger, embarrassment, sadness and eventually, even relief.” It is vital that family members and loved ones of a patient diagnosed with Alzheimer’s allow themselves access to their own care and support during this time. “A combination of a social worker, counsellor and support groups can play a huge role in aiding the family members to process their own loss and emotions, helping to provide structures and tools that allow them to be able to continue with their own lives during these difficult years and eventually, with time, to be able to let go.”

Alzheimer's Disease Early Warning Signs

A memory problem which is **NOT** caused by alcohol abuse or head injury, and which worsens with time.

Language problems. Difficulty naming objects, finding the right word to use in a sentence, and often speaking nonsense.

Zips and buttons are difficult to fasten. Alzheimer sufferers find it hard to dress themselves.

Hygiene. Those with Alzheimer's may not care about how they look and may not want to bath.

Extrême mood swings. A change in mood for no reason – going from calm to suddenly scared or angry and aggressive within minutes.

Impaired judgement. Strange behaviour – like wearing underclothes over outer garments or taking clothes off in public.

Many Alzheimer sufferers **get** lost in familiar places such as their own neighbourhood.

Even recognition of their own family and friends becomes difficult.

Recalls memories of childhood at times but cannot remember anything that happened the same day.

Suspicious of other people and may accuse them of stealing or hiding things.

