

Press release

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)¹.

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 cases².

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

¹ <https://www.who.int/news-room/fact-sheets/detail/dementia>

² <https://www.gov.za/speeches/world-alzheimers-day-2021-13-oct-2020-1357>

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 care givers.
- 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 and 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.
- **L**anguage problems. Difficulty naming objects, finding the right word to use in a sentence, and often speaking nonsense.
- **Z**ips and buttons are difficult to fasten. Alzheimer sufferers find it hard to dress themselves.
- **H**ygience. Those with Alzheimer’s may not care about how they look and may not want to bath.
- **E**xtrême mood swings. A change in mood for no reason – going from calm to suddenly scared or angry and aggressive within minutes.
- **I**mpaired judgement. Strange behaviour – like wearing underclothes over outer garments or taking clothes off in public.
- **M**any Alzheimer sufferers get lost in familiar places such as their own neighbourhood.
- **E**ven recognition of their own family and friends becomes difficult.
- **R**ecalls memories of childhood at times but cannot remember anything that happened the same day.
- **S**uspicious of other people and may accuse them of stealing or hiding things.

For assistance:

If anyone you know has a NUMBER of these signs, they should be advised to visit their doctor or you can contact Alzheimer’s SA. The organisation operates in 9 provinces, this contact number is the one to call to source a contact in your: 011- 7922511/ 063 6849158 or email info@alzheimers.org.za.

To find a social worker that works with dementia or Alzheimers, visit:
<https://www.saaswipp.co.za/social-worker-search>

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BIOGRAPHY: DR HEATHER RAUCH

Dr Heather Rauch is a social worker in private practice and is presently the Eastern Cape Chairperson of the South African Association for Social Workers in Private Practice (SAASWIPP) and the Vice Chairperson of the National Executive Board, having served two previous terms of office as a portfolio member.

Heather is also a director of the ECHO Foundation and a Board Member of the Aurora School for the profoundly handicapped. Heather has a Master’s Degree in Clinical Social Work as well as a Doctoral Degree in Social Work, both from the University of Port Elizabeth.

Heather started her career working in the Department of Health Services and Welfare before being appointed as the founder social worker for Childline, P.E. and the Child and Family Welfare Society. She worked at this unit for six years, where the skills were acquired to go into private practice in 1995, focusing primarily on psychosocial matters relating to families.

In 2007, Heather began her sessional work for the Alzheimer's Association, Eastern Cape and in 2014 became the Regional Manager for the Eastern Cape.

Competencies and interest areas

- Training and supervision of staff at FAMSA, Port Elizabeth on a monthly basis from 2008 to 2011.
- A trained mediator and regularly appointed as Parental Coordinator in various matters by the High Court and Children's Court.
- Assessments in family related medico - legal matters and the provision of expert evidence in the Children's Court, Regional Court and High Court.
- Research and practice supervisor of 4th year students at NMMU since 2013 and Master's students since 2018.

Heather has been married since 1985 and has two adult children, Pippa, a registered industrial psychologist and Simon, a medical doctor.

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