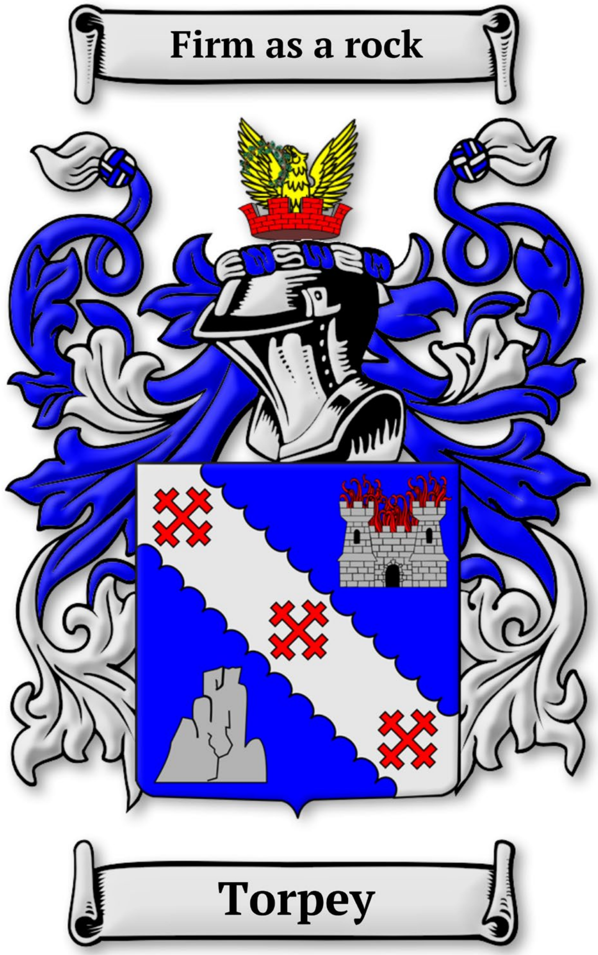
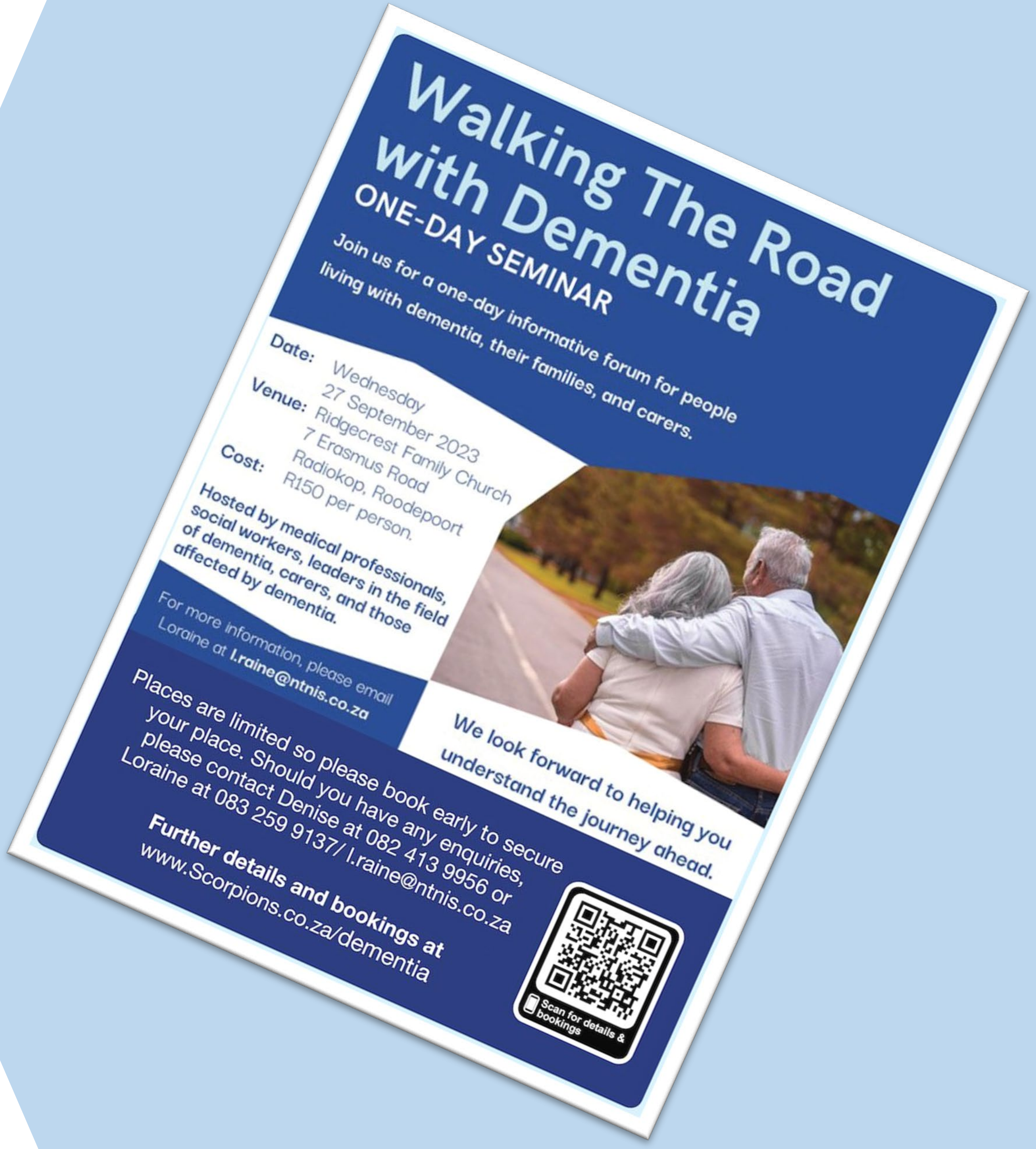
# PRESENTATION 27/09/2023

**Declan Torpey**

for and on behalf of the Torpey Clan





# Walking The Road with Dementia

## ONE-DAY SEMINAR

Join us for a one-day informative forum for people living with dementia, their families, and carers.

**Date:** Wednesday
27 September 2023

**Venue:** Ridgecrest Family Church
7 Erasmus Road
Radiokop, Roodepoort

**Cost:** R150 per person.

**Hosted by medical professionals, social workers, leaders in the field of dementia, carers, and those affected by dementia.**

For more information, please email Loraine at **l.raine@ntnis.co.za**

**We look forward to helping you understand the journey ahead.**

Places are limited so please book early to secure your place. Should you have any enquiries, please contact Denise at 082 413 9956 or Loraine at 083 259 9137/ l.raine@ntnis.co.za

**Further details and bookings at**
www.Scorpions.co.za/dementia

Scan for details & bookings

# Alzheimer’s: A Family’s Journey

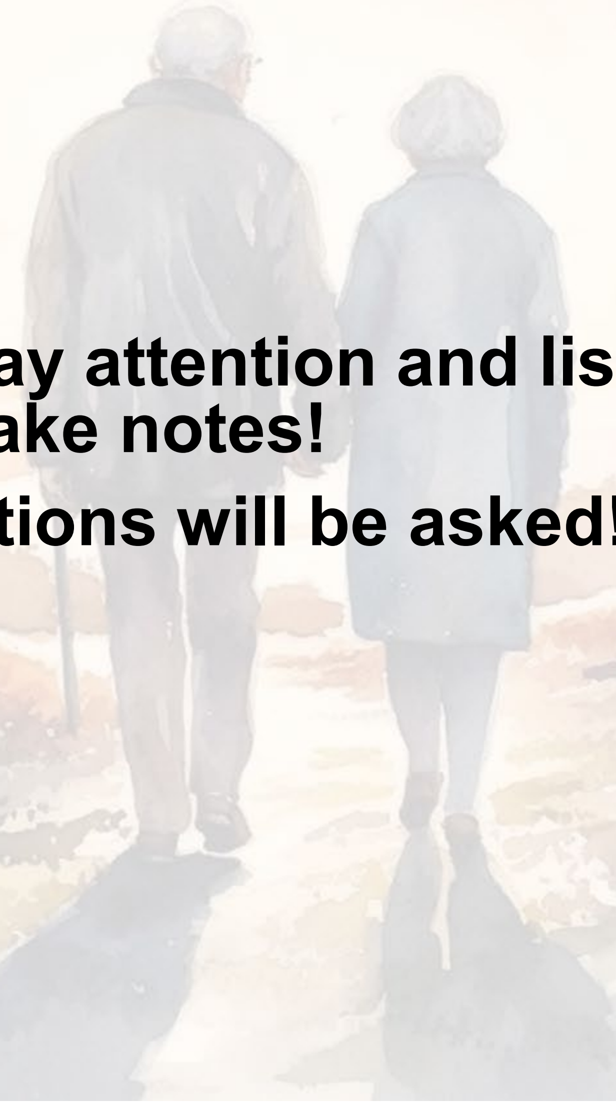
- **I extend thanks to all the amazing wonderful caregivers here today and dedicate this presentation to the two goddesses in my life, my wife, Renee are her dedicated caregiver, Gladys Methusi.**

Firm as a rock

Torpey

# Request

- I have only **ten minutes** to chat to you all, so my presentation will be cursory, as there are **30 slides** (that equates to 20 seconds-a-slide), but within the presentation there is useful information which **I hope proves is of use to you all**, as it has proven to be for me over the past **+-16 years of being the Principal Caregiver to Renee.**



- **So, pay attention and listen, and take notes!**
- **Questions will be asked!!**

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# Decisions

- In life one goes through highs and lows, and how you treat those emotional charlatans is largely **predicated on one thing, and that is attitude.** You can either allow them to define you and/or your life or see yourself and them all as cosmically unimportant. Certainly, I did not, and **will not, allow Alzheimer’s define my relationship with Love itself, or with Renee, and/or the Love inherent in my family.**
- I took a decision in the early days of Renee’s diagnosis that my marital vows of *“….in sickness and in health…”* had to mean something to me as a man and husband, therefore, **neither abandonment or divorce nor indeed a frail-care facility, would be part of my life path in her care.**
- Further, I took the decision that notwithstanding the challenges that Alzheimer’s would cause to befall on my family, **we all would live the best lives possible**, and the disease would not be a hindrance to our individual respective best lived paths.
- Renee would be cared for where and how the best medical advice available advised me, in as must as constraints with the Torpey Clan allowed. **Both I and the Support Team would do our best, but not to our detriment.**
- **I would show to my wife and family – but mostly my God and myself - what can be achieved with an unbridled commitment to Love.**

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# Renee Torpey: Goddess No. 1

- **Renee by profession was a neurophysiologist technologist**, working for many years in the Johannesburg General Hospital. Her specialisation was in the fields of the study of apnoea sleeping patterns, and brain injuries.
- **Renee was very active both socially and in sports.** She was involved in horse-riding, kick-boxing, squash and wind-surfing. She was always very fit and lithe in figure.
- **Renee was diagnosed when she was 50** but had been showing symptoms for about +-2 years prior to then. **She is now 64 and been living with Alzheimer's for +-16 years**. She is bed-ridden, incontinent, and has no remaining mental faculties. She is hand-fed liquidised meals. She has been in home-based-care for the whole period of her incapacitation.
- She has one sibling, a **brother, Colin**, who has remained steadfast by her side to today, throughout the many trials of this dreadful disease.

# Touchpoints 1 Of 2

## Personal

- Family
    - Declan: Principal Caregiver, engineer
    - Renee: PWD, Goddess No. 1
    - Joshua: Eldest son, lawyer
    - David: Youngest son, scientist
    - Gladys: 2nd. Caregiver, Goddess No. 2

- Support Team
    - Family
    - Extended-family and Close Friends
    - Medical Team
    - Ad-Hoc Team

## Presentation: Practical

- Assumes diagnosis of some form of Alzheimer's and/or dementia etc has been made.
- Symptoms are in very early stages.
- PWD is still legally competent. Vitally important to address all Legal and Financial matters in this phase.
- Decisions are about to be made as how to manage the care of the PWD, and as importantly, the care needs of both the Principal Caregiver and the Secondary Caregiver.
- All statistics noted in the presentation are sourced from the internet.
- An abridged copy of the presentation will be made available upon approved request.
- Please keep questions to the end of the presentation

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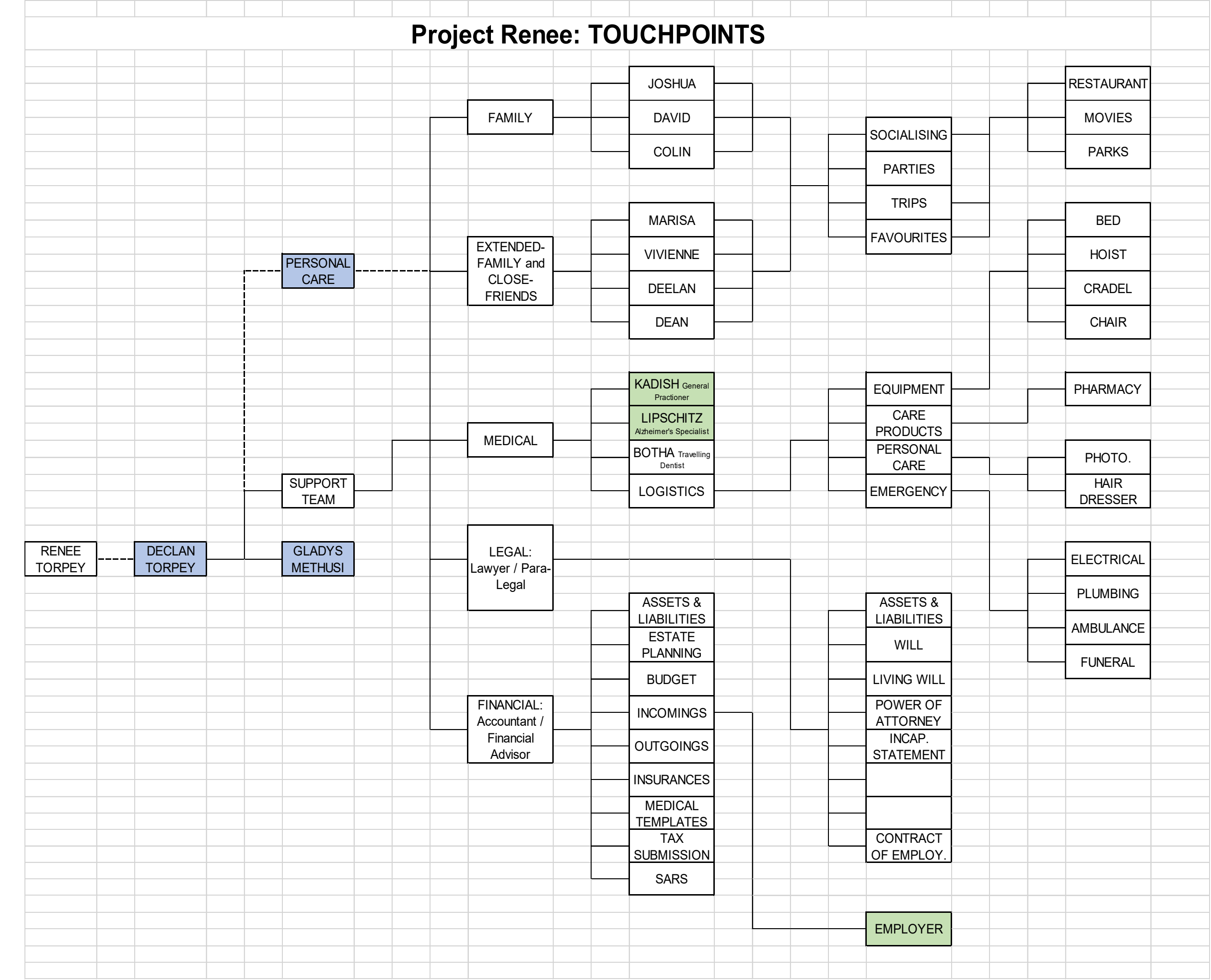
# Touchpoints
# 2 Of 2

## Principal Caregiver High-Level Organogram

Updated regularly as Renee’s care needs changed.



# Self-Help 1 Of 4

- **At the outset** – relying on my engineering profession skillsets - I did some strategic planning by way of a gap-analysis and made the tasks ahead for the **Torpey Clan: Project Renee.** A Torpey Clan website (located at Home | torpeyclan) was setup listing the doings of the family.
- **Gap-analysis covered the following:**
  - Personal and personnel
  - Legal
  - Medical
  - Financial
  - Practical (Caregiving)
- **Way-Forward covered the following:**
  - All gap-analysis shortfalls (personal, practical, logistical, infrastructure, financial etc).
  - Support Team will be empowered and empowering.
  - Ground rules and authorisations (no fair-weather supporters). No ‘hen’ supporters, only ‘bacon’ supporters will be allowed.
  - Semi-retirement for two-years to set-up the procedures, protocols and wherewithal's to ensure that the Project Renee was structured professionally

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# Self-Help 2 Of 4

- **Ethos Statement:**
    - **Love, Kindness, Respectfulness and Gentleness will prevail.**
    - We will remember that **our fragilities do no define our inadequacies, but rather our humanity.**
    - We will remember that the worst thing you can say about a man, was that he was at his best when times were good. **The Torpey Clan will show to one another that we were at our best when times were at their worst.**
    - **Alzheimer’s will define nothing negative about the Torpey Clan, individually and/or collectively.**
    - **Alzheimer’s is nothing, Love and Hope are everything.**

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# Self-Help 3 Of 4

## Worldwide

- **What and where are available resources and support in the management of Alzheimer's?** I limited myself to English speaking countries, specifically: Australia, Canada, Ireland, New Zealand, UK, and USA.

- **Listing of useful websites:** The below is a listing of website that I found useful in garnering and collating the knowledge touchpoints I identified in how to carry-out the management of Renee's care needs and my own wellbeing:
  - Australia: https://www.alzheimerswa.org.au
  - Canada: Alzheimer Society of Canada
  - Ireland: Home - Alzheimer
  - New Zealand: Alzheimers New Zealand
  - UK: https://www.alzheimers.org.uk
  - USA: Alzheimer's Association | Alzheimer's Disease & Dementia Help
  - Mayo Clinic: Alzheimer's disease - Symptoms and causes - Mayo Clinic

I have found that all of the websites – notwithstanding that they are all internationally based - were willing to help me and were unconcerned by the fact that I was located in RSA. They were willing to either give either – free of-charge – or at reduced cost, electronic access to much of the literature they produce.

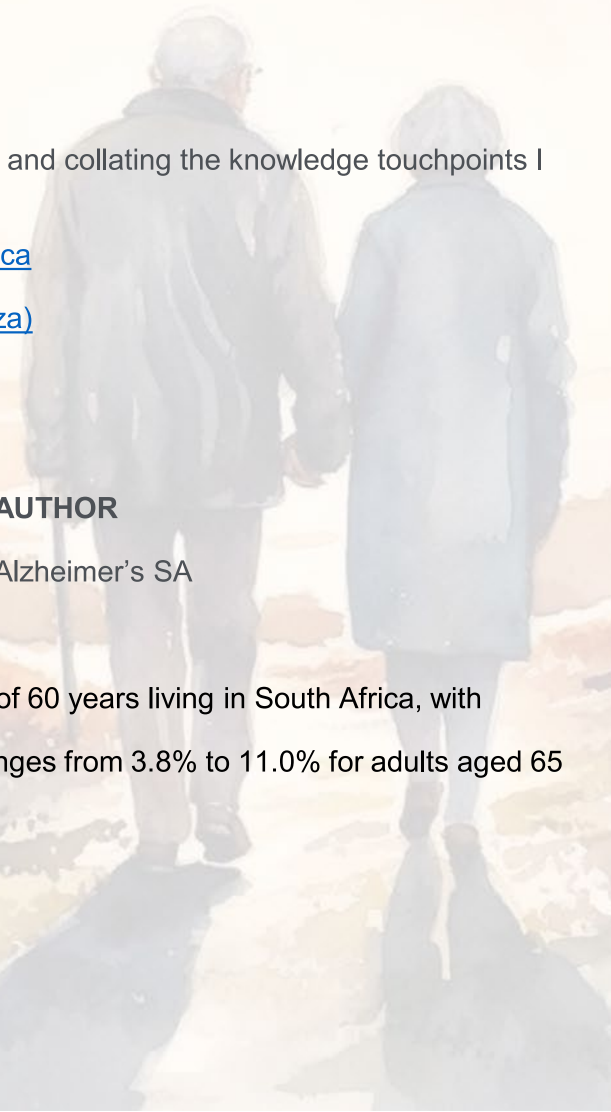
## Worldwide

- **Listing of reading material:** The below is a listing of materials I found useful in up-skilling both myself and the Support Team:

| TITLE | AUTHOR |
|---|---|
| Alzheimer's Early Stages | Daniel Kuhn |
| Alzheimer's Activities That Stimulate The Mind | Emilia C. Bazan-Salazar |
| Guide To Alzheimer's Disease | Mayo Clinic |
| A Basic Guide For Nurses & Caregivers On The Care & Management Of Alzheimer's Disease | Janice Mymin |
| Your Guide To Understanding Alzheimer's Disease | The Alzheimer's Society Of Ireland |
| Alzheimer's Disease Handbook | Cornelius Kelly |
| Overcoming Everyday Challenges In Alzheimer's Books I and II | Alzheimer's SA |
| Alzheimer's And You: A Self-Help Guide For Carers and Sufferers | Jane Hill |

- **Listing of further reading material: and websites:** The below is a listing of materials and websites that I found useful in up-skilling both myself and the Support Team:
  - Professionals-Guideline-FullReport-CA.pdf (alzheimersla.org)
  - PG_ALZ_00pre(1-6).fm (psychiatry.org)
  - Present Algorithms and Future Treatments for Alzheimer's Disease - PMC (nih.gov)
  - Microsoft Word - What Is Alzheimer.doc (accessiblehomehealthcare.com)
  - Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging (nih.gov)
  - To accelerate search for an Alzheimer's cure, scientists use artificial intelligence to identify likely drug targets | College of Medicine - Tucson (arizona.edu)

# Self-Help 4 Of 4



## RSA

- **Resources in RSA:**
  - **Listing of useful websites:** The below is a listing of websites that I found useful in garnering and collating the knowledge touchpoints I identified in how to carry-out the management of Renee's care needs and my own wellbeing:
    - South Africa Home - Alzheimer's South Africa (alzheimers.org.za)
    - South Africa Dementia SA | Managing Alzheimer's and dementia care in South Africa
    - South Africa Alzheimers & Dementia in South Africa (worldlifeexpectancy.com)
    - South Africa Old Age Homes With Dementia / Alzheimer's care  (seniorservice.co.za)

- **Listing of reading material:**
  - The below is a listing of materials I found useful in up-skilling both myself and the Support Team:

| TITLE | AUTHOR |
|---|---|
| Overcoming Everyday Challenges In Alzheimer's Books I and II | Alzheimer's SA |
| Book Catalogue - Alzheimer's South Africa (alzheimers.org.za) | Alzheimer's SA |

- **Statistics In RSA**
  - A recent World Alzheimer's Report estimated that there were 4.4 million people over the age of 60 years living in South Africa, with approximately 187,000 living with dementia.
  - Estimates from studies conducted in South Africa indicate that the prevalence of dementia ranges from 3.8% to 11.0% for adults aged 65 years or older.

# Statistics and Information 1 Of 1

## Worldwide 1 of 2

- **What is young-onset Alzheimer's?** Young-onset (also called early-onset) Alzheimer's is an uncommon form of dementia that affects people younger than age 65. About 5% to 6% of people with Alzheimer's disease develop symptoms before age 65.

- **Early-Onset Alzheimer's:** A small number of people have "early-onset" Alzheimer disease, which starts when they are in their 30s or 40s. People live for an average of 8 years after their symptoms appear. But the disease can progress quickly in some people and slowly in others. Some people live as long as 20 years with the disease. Renee is presently tracking +- 16 years.

- **Age Group Of Early-Onset Alzheimer's:** The disease occurs between a person's 30s to mid-60s (Renee was in her late-forty's when she first exhibited symptoms) and represents less than 10 percent of all people with Alzheimer's. Some cases are caused by an inherited change in one of three genes. For other cases, research shows that other genetic components are involved. In Renee's case, there is no genetic predisposition.

## Worldwide 2 of 2

- **The 7 Stages of Alzheimer's Disease**
- Stage 1: Before Symptoms Appear. ...
- Stage 2: Basic Forgetfulness. ...
- Stage 3: Noticeable Memory Difficulties. ...
- Stage 4: More Than Memory Loss. ...
- Stage 5: Decreased Independence. ...
- Stage 6: Severe Symptoms. ...
- Stage 7: Lack of Physical Control.

- **Late-Stage Problems:** It is quite common for a PWD, especially in the later stages, to spend a lot of their time sleeping – both during the day and night. This can sometimes be distressing for the person's family and friends, as they may worry that something is wrong. It has attendant problems that feeding and nappy changes becomes increasingly difficult because the increasing non-responsiveness and non-mobility of the PWD.

# Support Team 2 Of 2

## Gladys Methusi

- I cannot speak highly enough of ‘our’ Gladys. I and the whole Torpey Clan, Support Team (particularly her doctors) recognise that we would not be where we are in our care of Renee without Gladys amazing committed efforts and work. It has been nothing short of exemplary. The woman is a lady and fondly known as Goddess No. 2.
- Her training has been in-house (by me) – from guidelines sources in RSA, Ireland, USA etc – and on-the-job training.

  Renee’s longevity is due in no small part to what Gladys has largely done, alone. This family owe a debt of gratitude we can never repay.

## Dr. Botha

- Dr. Botha and her team are available for home visits dentistry.
- My focus in finding a home dentist was to keep some level of optimal oral hygiene – by at least yearly appointments – and being aware if Renee’s teeth needed any attention (by way of fillings/removal etc).
- The services have always been professional, non-intrusive and prompt. Renee experienced as little distress as was possible due to the care and attention of Dr. Botha.
- Always Renee’s teeth were given a thorough cleaning.

# Support Team 1 Of 2

## Dr. Lipschitz

- Initial confirmation of diagnosis.
- During the early stages of the disease carrying-out MSE tests and prescribing such medications as were available. And being a proactive adviser of the likely next stages and symptoms of the disease.
- In the latter stages of the disease when medications were no longer impactful, being a ‘friend’ and a wonderful sounding-board of my emotional wellbeing.

## Dr. Kadish

- Being a home-visiting doctor (unique to Renee) to look after Renee’s general wellbeing, assuring we as carers were not missing anything substantive in her medical care.
- Being an amazing ‘friend’ and an impactful sounding-board of my emotional wellbeing, and my personal health generally.
- Always being an amazing support for and of the Torpey Clan.

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# Support Team: Daily Tasks 1 Of 3

## Daytime

- **Morning:**
    - Change nappy, and clothes (if soiled)
    - Change bedding and liners (if soiled)
    - Breakfast
    - Brush hair
- **Mid-Morning**
    - Change nappy
    - Snack and drink
- **Lunch**
    - Meal and drink
- **Mid-Afternoon**
    - Snack and drink
- **Supper**
    - Meal and drink
    - Bed-bath and oil skin
    - Brush teeth
    - Change nappy and clothing

**Early-Evening:**

- Make sure restful and sleeping

## Nighttime and Weekends

- **Nighttime**
    - Check is restful
    - Check posture is comfortable
    - Move intermittently
    - Check not soiled
- **Weekends**
    - Full bath
    - Visitors
    - Social engagements

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# Support Team: Daily Tasks 2 Of 3

## Social / Entertainment 1 of 2

- At all times interact and talk to the PWD as if they still have their full mental faculties.
- Validate the importance of their presence.
- As the disease progresses the following may prove of use in fulfilling the day for the PWD with some levels of enjoyment:
  - When PWD can no longer understand verbal communication, use of silent movies (from the early-1900) will prove entertaining as the humour is visual.
  - Use of large pieces children's jigsaw puzzles may help is stimulating interactive fun.
  - Outside walks in supervised safe controlled garden may prove refreshing.
  - Takes comfort in old photographs or old item of clothing etc.
    - Engagement photograph story.

## Social / Entertainment 2 of 2

- I tell Renee every day how important she is, how much she is loved and how wonderful she looks. That she may sleep through all my talking is unimportant.
- During the concurrency of the disease people fall-away. Eventually one finds out the true nature of both family members and supposed close-friends.
- As the mental faculties of the PWD fade away, understand that he/she can become increasingly fearful of:
  - Being outside
  - Being in crowded and/or noisy environments
  - Water (bathing)
  - Dressing (with bouts of inappropriate disrobing in public)
  - Garbled shouting and cursing foul language
  - Violent outbursts
  - Wandering incessantly

# Support Team: Daily Tasks 3 Of 3

## Caregiver Solutions 1 of 2

- **Bedsores**
  - These are to be treated immediately
    - Learn how to dress wounds from an ICU nurse.
    - Have well stocked medical cabinet
      - Stocked with medicines, bandages, plasters, scissors, towels, wet-wipes etc.
  - Use of lambswool cushions to be used on touch and pressure points
- **Falls**
  - Be careful with the progression of the disease the PWD will lose ability to stand and walk.
  - When a fall occurs look over the whole naked body at regular intervals for bruising, bumps, grazes and inflammations, particularly if the PWD has lost mental faculties and is unable to talk.
- **Equipment**
  - **Bed**
    - Have a hospital bed, that allows multiple tilting functions
    - Spray bed frame with indoor insect repellent and use overhead mosquito nets
    - Have immediate access to supplies (care and medical)
    - Have immediate access to mobile spotlights (for lighting of wound dressing)
    - Bedding:
      - Use multiple light blankets rather than single heavy blanket/duvet, makes controlling of body temperature inside the bed easier
      - Use multiple mattresses (orthopaedic and foam)
      - Use bedliners (and change regularly when PWD is incontinent)
  - **Bath**
    - Have seating chair
    - Have non-slip mats
    - Have hoist (with capacity of 250kgs)
    - Have cradle to lit PWD from wheelchair to bath
  - **Mobility**
    - Have a wheelchair
    - Make sure patient torso is tied to the back of the chair when core strength is lost and the PWD is unable to sit upright

## Caregiver Solutions 2 of 2

- **Nappies**
  - Open type nappies are easier to use in later stages when PWD is bed-ridden.
- **Bodily Care:**
  - Teeth brushed daily. Possible use aqua brush.
  - Nails to be cut monthly.
  - Ears to be cleaned monthly (not by use of ear-buds).
  - Skin to to be covered with nappy-rash cream daily, particularly in arm pits, hips, groin etc.
    - Skin to be thoroughly inspected for pressure sore and inflammations on at least a weekly basis, and daily with bed-bath.
    - Look for bedsores in ankles, groin, hips, posterior etc.
- **Dressing:**
  - Open loose clothing
  - Multi-layered clothing
  - Be careful of gaudy designs or patterns to clothes as they may cause distress to PWD
- **Washing:**
  - Daily bed-baths must be given
  - Weekly full immersed baths to be given with soluble oil added to the water.

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# Practicalities:
# Things To Do 1 Of 2

## Financial 1 of 2

- Consideration needs to be given that all of the following are put in-place.
- Accountant / Financial Advisor (hereafter AFA)
  - The AFA (with expertise in the fields investments and taxation) for persons with mental and physical incapacitation
  - AFA and Principal Caregiver to put in-place all of the below documentation.
  - Ensure (particularly if spousal relationship is in-place) that all assets and liabilities of both the PWD and the Principal Caregiver are clearly and comprehensively identified and signed-off by both the AFA and Lawyer.
- Budgeting
  - Monthly
  - Yearly
  - Projections
    - Living Expenses
    - Support Team
    - Medical
      - Medical Aid
- Assets and Liabilities (on the assumption of spousal relationship) have estate planning in-place
  - Principal Carer
  - PWD

## Financial 2 of 2

- Insurance
  - Principal Carer
  - PWD
  - Visitors
- AFA
  - Have SARS submission template in-place
- SARS
  - Register PWD
  - Have yearly submission protocol in-place with AFA collating all medical expenses.
- Bank / Investments / Savings Accounts
  - Close or otherwise as advised by AFA.
- **NOTE: The above and opposite listings ARE NOT A FINANCIAL OPINION and it is incumbent on you and your Support Team to all times act In the best interests of both the PWD and the Principal Caregiver (and 2IC) such that no statutory, regulatory or legal impediments cause unintentional harm to the financial needs of the PWD.**

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# Practicalities: Things To Do 2 Of 2

## Legal 1 of 2

- Consideration needs to be given that all of the following are put in-place.

- Lawyer
  - Put in-place a family lawyer (with expertise in the field of family law, mental and physical incapacitation).
  - Family lawyer and Principal Caregiver to put in-place all of the below documentation.
  - Ensure (particularly if spousal relationship is in-place) that all assets and liabilities of both the PWD and the Principal Caregiver are clearly and comprehensively identified and signed-off by both the AFA and Lawyer.

- Put in-place the following documentation:
  - Will
    - Of the PWD
    - Of the Principal Caregiver
  - Living Will (and Funeral Arrangements)
    - Of the PWD
    - Of the Principal Caregiver
  - Power Of Attorney **(other statutory options discuss with lawyer)**
    - Authorising the Principal Caregiver and/or his/her 2IC to act for and on behalf of the PWD in the event of their incapacitation.

## Legal 2 of 2

- Put in-place the following documentation:
  - Custodian (appointed by High Court)
    - In the event of the incapacitation of the PWD and no Principal Caregiver is in-place.
  - Contract Of Employment
    - Detailing comprehensively the tasks of the Secondary Caregiver.
  - Principal Caregiver: Incapacitation Statement
    - Detailing procedures and protocols to be followed by the Support Team in the event of incapacitation of the Principal Caregiver and the appointment of 2IC.

- **The above and opposite listings ARE NOT A LEGAL OPINION and it is incumbent on the Support Team to all times act in the best interests of both the PWD and the Principal Caregiver (and 2IC) such that no statutory, regulatory or legal impediments cause unintentional harm to the legal needs of the PWD.**

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# Alzheimer’s Realities

## Bad

- Medical science cannot impactfully change the inevitably of the prognosis and progression for the sufferer.
- There will be arduous and frightful days.
- There is a dreadful inevitability in the symptoms of the various stages of the disease.
- Whilst the sufferer has an awful path, so too can the carers and close family carry real concomitant frailties, both physical and emotional.

## Good

- With hope in one’s heart and an unbridled relationship with Love, and a cohesive and impactful Support Team, and large doses of bloody-mindedness, you will be amazed at what can be achieved.
- I am hugely proud of what has and is being achieved in the care of my Goddess.
- The disease does not define anything substantive in my life, neither my relationship with Love, the love I have of my Goddess, nor the Love in my home.
- Who and what we are is measured by what we have done and continue to do, and not how we have and continue to suffer. Alzheimer’s is only a disease it is nothing compared to Love.
- I am a lucky man because in my life I have experienced both Love and Unrequited-Love. Few men get to experience the joys of such Loves.

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# LESSONS LEARNT

- As with most things in life, attitude is everything. I took the decision that Love will define The Torpey Clan and not, and never, Alzheimer’s.
- A hard lesson learnt is for caregivers to look after yourselves firstly, not after the PWD. And in that, I mean your personal health, emotional wellbeing, financial standing, social interactions, frequent breaks for ‘me-time’ – away from all the doings around being a caregiver and Alzheimer’s - and as additionally you may need. Do not sacrifice yourself. I did not take care of myself properly in the early-days of Renee’s care, and I paid a difficult price.
- E-mails are a useful tool to keep links within the support Team and send update reports-backs to family and close-friends. (Also, they are a most useful historical record to track on the progression and regression of both the disease and how it impacts Renee).
- Understand a harsh reality: that however bad the situation is now, without you as the Principal Caregiver, it will be very much worse, not just for the PWD, but also for family and friends. As the Principal Caregiver, you are the boss, no one else.
- Be decisive in your decision-making, and do not allow intrusion by family and/or friends, no matter how well-meaning they may be. And more and most importantly, be gentle and forgiving on yourself for any mistakes you may make.

# A Hope And A Prayer

- *"…….Remember, hope is a good thing, maybe the best of things, and no good thing ever dies. I will be hoping that this finds you, and finds you well….."* and in your own good time of pause and reflection, that this presentation resonates with you at some impactful level.
- I remind my Family and Support Team that when Renee dies and we are individually or collectively in that lonely place of grief and dread, that what we have done, those many, so very many good and wonderful things over these past +-16 years, all of them no matter how big or small, will prove a succour and assuage our grief. It's in our DNA.
- Because good people do not take their grief to an ego place of self-absorption, but rather to places of remembrances, of times shared and joys experienced.
- And of those times and joys, we were, always and forever, blessed one and all, because for a time we shared our lives with a Goddess (Renee), and during those days we shared them with another Goddess (Gladys) by our side, helping us all the way.
- That the Gods continue to be most kind to the Torpey Clan.
- My last hope and prayer for you one and all – particularly the caregivers – is that you are gentle on yourselves and know that with hopefulness (and a plan) you'll be amazed at what can be achieved with Love as a guiding light.

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# Thank You

- Comments and Edits
- Questions
- For an abridged copy of this presentation please contact me at declan@ibi.co.za
- Contact details of doctors noted in presentation are available upon request.