

Episode 13: Living with Dementia; An Interview with Tommy Dunne Show Notes

- 1:42 The best way to communicate with someone with dementia
- 2:06 Person Living With Dementia often calls for their mom and dad
- 2:26 I'm not sure, I haven't seen them lately" validate
- 2:38 Don't ever keep telling them they loved ones are dead because they re-live the grief as if it's the first time they are hearing the news

- 2:56 Avoid arguing with a person with dementia
- 3:05 Want to go home - "what's home look like?" Get them to describe their home

- 3:20 Divert the questions/conversations
- 3:27 Keep a log because you can see what behavior triggered it
- 3:45 Who are you?
- 4:00 If someone is in their teens they might not recognize them only as a baby
- 4:33 Hard to start a conversation with a newly diagnosed person because they're in shock

- 4:45 They are defensive
- 5:00 Implications of denial are very serious
- 5:08 Alz will not wait for you to accept it
- 5:16 Hard for family to accept it - took son & daughter a year to accept it
- 5:55 Wife volunteered him to talk to others
- 6:50 He said he had lost his ability to talk, developed a stammer after diagnosis

- 7:58 At event, he said that's not what it's like living with dementia
- 8:29 Being able to go there and speak gave him the confidence to grow
- 8:56 Dementia gives you a Superpower
- 9:00 September 19, 2011 was when he was diagnosed
- 9:43 When the superpower kicked in - Invisibility
- 9:58 Thought he knew what loneliness was but he was wrong
- 10:35 Uneducated, frightened of it - afraid they can catch it
- 11:01 Associate dementia with demented
- 11:14 Alz is just one type of dementia - some people think it's better to say Alzheimer's instead of dementia

11:40 Children had had time accepting the diagnosis
11:50 If diagnosed with cancer care plans would have been in place but not with dementia

12:06 You are stigmatized

12:20 Son didn't want his daughter to be in a tv segment because he didn't want her to be bullied at school because Tommy had dementia

13:00 "I'll change the world til people accept dementia"

13:36 Dementia is getting talked about everyday now

14:00 People don't want to put the diagnosis out there because of the stigma

14:15 Have you lost friends?

14:36 Made great friends with dementia now

14:53 Want people to laugh with us not at us

15:10 A good friend can hear what you say when you say nothing

15:38 What has changed with your senses, etc?

16:00 It's about your cognitive skills and your perception skills

16:10 A black mat looks like a hole to him

16:29 Black and white tiles on the floor looks like steps

16:40 Polka dots on someone's shirt looks like they're moving

16:54 He would say that Caregivers need to put themselves first - have to put yourself before the person you're caring for

17:08 If carer goes down you're going to need 2 carers

17:18 They need to have a break

17:21 If you're around dementia 24/7 it will take them down

17:25 It will take them down quicker than the person who has it - they're easy targets

17:55 People don't see what caregivers go through

18:02 No such thing as a perfect carer - It's alright to make mistakes - don't be too hard on yourselves.

18:12 Have to be realistic to what you can achieve

18:17 Sign of strength to ask for help before they become ill or stressed out

18:30 You have to do it before you get to that point where they're going to need the caring

18:43 Society assumes it's your responsibility because it's your mother or father or husband but caring 24/7 - we are not built for that

19:00 Humans are not built to care 24/7 with that pressure

19:15 Caregivers need a break

19:47 Caregivers can sometimes feel guilty

19:52 Guilty about moving them into a home, betrayal, let them down

20:26 It's impossible to look after them when they reach that stage - they're still strong people if they want to go out, they're going to go out

20:45 Caregivers need to relax, need to be pampered and looked after

20:59 It's easy to feel trapped because you are devoting yourself to care now - gave up what you wanted to do in life

21:25 It's easy to get frustrated

21:36 Person with dementia will forget what you said but will remember how you made them feel - emotional memories stay, the words are forgotten

21:57 He makes sure his wife goes out

22:25 Dementia comes and sits some days and makes him not nice

22:33 "The Black dog days" - no matter what you do you can't lift yourself up

23:02 Are you aware of being in that space with the black dog?

23:12 It's like standing beside a person, an out of body experience

23:43 You are aware of what's happening

24:00 "Don't speak to them because they don't speak back" breaks his heart

24:10 We may lose our ability to communicate but we don't lose our intelligence just our ability to communicate

24:21 Non verbal ways to communicate

24:34 Imagine being in foreign country - we may not get all of the message

24:45 With Alz you only get parts of the message

25:18 He could never understand how people will talk to plants and animals and pets but they won't talk to people with dementia because they say they don't understand - it doesn't make sense

25:47 "I don't know how to talk to someone with dementia" - Just talk

26:12 Need extra time - We process it in time, in that few seconds of silence the carer isn't comfortable and answers for them

26:39 Just give us the time to answer the question, you might be surprised with some of the answers you get, some of the knowledge you'll get

27:09 What is it like after the dark space

27:13 Tommy tries to write it down to tell people about that experience so they can learn from it

27:35 Give the person with Dementia space, Don't keep asking questions, it's overload

28:21 Let them be if they are in that space

28:57 Does appetite change?

29:07 He never feels hungry or thirsty

29:18 In life we live by the clock, breakfast at a certain time, lunch at a certain time, dinner, tea, but with Alzheimer's, just because clock says it's a certain time doesn't make I'm hungry

29:36 Better off with snacks

29:58 He can't even force himself to eat it he's full

30:07 Certain times everything tastes like bleach or smells like bleach

30:20 He knows there wouldn't be bleach in it but that's what it tastes like

30:42 People in the hospital - they put water next to the bed but PLWD but because they don't feel thirsty they won't drink it - then they change the water and the other person thinks you've drank the water

31:03 Don't drink then get dehydrated, then get delirium, if you're in the hospital then they move you to a home, then they get anti-psychotics

31:26 Same with food - they take it away and no one makes any notes saying they didn't eat it and before you know it they're on a hunger strike

31:56 He has a big sweet tooth

32:19 What does food look like to you?

32:22 Just doesn't look appetizing

32:30 The signals to tell you you're hungry aren't getting there

32:38 If you always feel full it doesn't matter what you put down in front of us

32:50 Driving

33:12 One day he got lost driving to the doctors

33:29 All the roads looked like strings, looked like a string city, you're mind goes back to how it used to look like

33:49 One of his scariest experiences was he was in the supermarket with wife one day, she went off to get something he couldn't see her and he started to panic - all the aisles were long and confused him - started to panic he could feel himself shaking and she came back and asked what's wrong? He said he had to get out

34:42 Everything changes just because you have done it forever doesn't mean you can

35:06 You know what to do your brain knows what it wants to do but it won't happen - you're telling your body what to do but it won't do it. That's the danger of driving the car, you're telling your left foot to do something but it just can't happen.

35:36 Others don't want to see that you can't do

36:15 Doing things like putting a coffee pot in microwave, do you know what you want to do but it just doesn't work?

37:07 if you're going to put something in the microwave but it looks like the refrigerator but in that moment it looks like that

37:38 What would you tell someone who just got the diagnosis

37:47 Life does not end with a diagnosis of dementia - you don't go right into the last stage - lot of living to be done before that stage

38:00 For your family's sake, get your paperwork in order while you can - Power of Attorney, Health POA, resuscitate not, funeral plans - try to save your family the heartache later theres enough to go through.

38:33 You have enough to go through

38:55 You live one day at a time you don't plan ahead but you HAVE TO get all of that paperwork done for your family

39:10 Bad enough they're losing you while you're still here, you're not the same person that they knew

39:20 His wife grieved for 3 years after his diagnosis - she grieved for the Tommy she married instead of the stranger she's living with now

39:43 He lost his empathy, he writes himself notes to give his wife a hug because it's not natural anymore - to get her flowers or tell her she looks nice

40:12 You save yourself a fortune over the years

40:25 Live for today, have a positive outlook on life, don't let dementia beat you, there's always hope, the darkest hours are always before the dawn

40:44 What would he want caregivers to know dealing with, interacting with, trying to support and being a care partner to anyone living with dementia

40:55 Give person as much independence as they can while they can, don't do everything for them if they can

41:18 There will come a time when they won't be able to so let them do it now

41:35 Get them out into society

41:45 Don't worry about what people think

42:00 Have to take away the fear and the stigma of dementia

42:10 Stop saying suffering there is no pain aside from the stigma

42:36 Can still live a good life, it will be different but you have to adjust

42:44 You've got to live

42:56 Best thing you can do is spending time with someone, giving someone your time is the best present you can give

43:19 Sleep

43:37 He practiced mindfulness from the time he was diagnosed

44:07 He knows peers that have trouble sleeping

44:18 He's never been afraid of death

44:28 If he dies, it's his time to go but people worry about it

44:36 He loves living, he respects that, he doesn't fear death

44:49 Terrible Nightmares, really really bad that you can't wake up from - he's had some where he's woken up but was still asleep very frightened

45:10 The dreams are so real like you're in a film, really real - you wake up exhausted, like you ran a marathon

45:29 He would describe living with dementia as like being on a treadmill - you're looking at the blank wall and you have to keep going and you have the little safety thing on, so if you go back it will stop it (that's you're carer) if you go to your left or right too much the carer will stop you, if the carer keeps hold of me I cannot move properly so I have to use a lot of energy just to stay in the same place everyday as I am today, I have to use more and more energy and eventually the treadmill will get faster and faster and I won't be able to stay in that same place and then I'll come back. But if the carer keeps too strong a hold of the safety thing and I go back it'll break and I won't be able to get back on the treadmill because it will just keep going.

46:46 Delusions

46:55 Sees people in the room, it's not a shadow it's an actual person

47:17 He really thinks they are there but he knows he is home and his wife wouldn't let anyone in

47:33 The other thing that scares him sometimes is he looks in the mirror and he sees his dad in it. You forget that you are this older person now.

48:08 One night when he woke up it around dawn, the light was just coming in the room and at the back of the door the grim reaper was there but it was the house coats on the back of the door - now there's not house coats on the back of the door.

49:02 It's like someone coming up and saying boo

49:23 Nothing worse than thinking someone is in the house that shouldn't be in the house

49:25 Moved houses used to have big house with stairs but always missed the bottom three stairs spent more time on the floor, wife called him Lionel

49:57 Now he wakes up and doesn't recognize where he's at that he's now in a bungalow

50:11 How do you take information in?

50:29 You do the cognitive testing - he can't do 3 words - can't do numbers - Doesn't recognize money - Can't count forward or backwards - can't count back from 20 - he forgets what he's doing

51:08 People say "how can you have dementia and you still talk?"

51:25 He traveled on a bus when he was first diagnosed - they have disabled seats, long seats on the side of the bus - girl whispered to her fellow, he said "excuse me mate you can't sit there, they're for disabled people"

53:01 First thing you do every morning when you open your eyes is please God let that be the nightmare, when it isn't you have to have something to get out of bed for

53:18 Mine is to dispel the myths of living with dementia, take the fear out of dementia take away the stigma of dementia - If you want to know what's it like to live with dementia you have to ask the person living with dementia if you want to know what it's like to be a family carer you have to ask the carer

53:47 Cannot think of any job that is any harder in the world than to be a carer

Dementia Diaries <https://dementiadiaries.org/>

