

Rotten eggs!

After caring for wife Kathryn at home for several years, **Ian Wilson** of Taumarunui reluctantly accepted the need for residential care. Ian shares his advice for other couples adjusting to this big change, and how to support grieving children.

When you are a sole charge carer for a loved one things are often rushed, as there is always so much to do.

I remember very lovingly deciding that a nice fresh country breakfast of bacon and eggs was on the menu for Saturday brunch.

My kind nine year old son had diligently gathered some free range eggs from the nests in our chook shed. Admiring my eggs simmering on the stove, and the soon to be devoured bacon, I was catastrophically involved in what seemed like a nuclear explosion. Covered in rotten eggs, and the foul stench of defeat, I wandered incredulously around the kitchen. Rotten eggs dripped from every surface, even the ceiling. He had gathered

rotten eggs, I don't know from where!

It seems sometimes we are given just a clutch of rotten eggs, one after the other. They say adversity brings strength, but to be honest I reached a point last Christmas where I was not very strong. Something snapped, and I pleaded with the divine powers to let some sort of change happen. It did, though not in a good way.

TRANSITIONS

I had given up work to support my son and my wife at home. Even with all the hospital loan equipment such as hoists and electric beds, I did not expect the stroke that forced me to evaluate my ability to care for Kathryn properly at home.



Care + Children

Firstly, love them through it! Not being a walkover helps, as the stresses of caregiving can make you damn irritable at times.

Transitioning a parent or any loved one from the family home to formal care can be very stressful for kids. Mum (or Dad) is gone from the family home, leaving a huge gap. In my opinion it is important to take away the mystery of caregiving, and let the kids know that their Mum or Dad is in trained and capable hands.

Although I notice some nurses are bashful about getting praise, showing thankfulness is something kids should learn in these situations.

Restless children will get bored quickly when visiting a care facility or hospital. The novelty of blowing up rubber gloves to make cow udders soon wears off! Giving them little tasks is sometimes useful, like collecting the dinner, or helping in the kitchen if busy staff will allow this. If there is a TV, and none of the residents are watching it, this can help to stave off boredom.

I think it's important for kids to understand that rest homes and hospitals are places where people can be a bit tired, sick or just plain grumpy.

Being courteous to staff and residents is important for them to practice.

I am sure not everyone can handle the challenges of caregiving, and we all react differently to stressful situations.

Kids are the same. My son accepts the situation but does not like to talk about it. So a tip is to not force a child to talk about every detail of their parent's care and health situation. Encourage them to talk to their Mum or Dad (even if they don't get an answer). Due

to her stroke, my wife fully understands what is being said, but cannot always readily reply. We have all had to learn to communicate patiently.

SLEEP DEPRIVATION, HIGH RENT, AND LOOMING DEPRESSION FORCED A RETHINK. HAMISH AND I MOVED BACK TO THE FARM, LEAVING KATHRYN IN THE CAPABLE HANDS OF THE PROFESSIONALS.

Was I just keeping up appearances trying to manage my wife's growing support needs, or simply struggling in a general way, as males are inclined to do? Well, that last stroke was a rotten egg. The ambulance left with my wife, and she never returned to the family home again.

A stay in hospital soon led to a decision that her condition was too unstable for me to deal with alone. A local care facility had a room to spare in its total care unit.

There, my young wife endured her first night listening to a screaming dementia patient next door. I broke out in a sweat thinking of her having to live there.

Elderly people can change with

conditions like dementia. I was green, and not at all tolerant of this behaviour. I feel guilty now about how I used to mutter under my breath for them to be quiet.

My son and I visited my wife every night, but soon she was unable to communicate with us. I decided to stop receiving the Care of Sick and Infirm benefit, as it had done its job when I was caring for Kathryn at home.

RETHINK

I looked for work, and we shifted to Hawkes Bay after I accepted a job there. Ambulance transfer fees were not affordable at the time, so the nurses and I bundled Kathryn into our Fairmont and we travelled to our new town, leaving the family home to wallow in disrepair for nine months.

It was a tough time, adapting to a new and very difficult job, renting a small sleepout, visiting Kathryn each night at her new care facility, and helping Hamish settle into his new school. We lived on a rural property with 20 ducks that quacked uproariously at 5am each morning. Funny it was not!

Sleep deprivation, high rent, and looming depression forced a rethink. Hamish and I moved back to the farm, leaving my wife in the capable hands of trained caregivers. >

WAYS TO HELP KIDS COPE WITH ILLNESS AND LIFE-THREATENING DISABILITIES

- Keep them informed.
- Keep loving them.
- Keep them involved in family duties.
- Let them know it's OK to feel sad sometimes.
- Be positive and count blessings.
- Talk about how they feel (don't force this).
- Don't let the situation drag you down financially; have the odd treat or holiday when possible.
- Keep parenting together even if one of you lives in a care facility.
- Maintain relationships with friends and family for fun times and stability.
- Ensure the child communicates directly with the other parent, not just through you or others.





THE TIME MAY COME TO LET GO AND TRANSFER THE CARING RESPONSIBILITIES TO TRAINED PROVIDERS ... THREE SHIFTS OF THEM!

Yes, trained, and three shifts of them a day. I was carrying the weight of the world on my shoulders and knew I could no longer provide the 24/7 care she needed.

My message really is to say that for those guys and girls out there struggling to continue caring, the time may come to let go and transfer the caring responsibilities to trained providers ... three shifts of them!

It can be hard to let go. You have to have real faith in the care facility and the honesty of the staff who, 99% of the time in my experience, do a wonderful job.

'My' nurses demanded new makeup for my wife, as what I had supplied was 'too old-fashioned'. Naturally, I was delighted to shop for new makeup, guided by them!

So here I am, back home, about to return to my old job, and alone again. It's a rotten egg for our little family, but we remind ourselves to get back on the horse and carry on.

ACCEPTANCE

We have been visiting Kathryn during the weekends and, without the day to day strain of caring, can spend good quality time together.

My last comment is that it is OK to feel happiness despite the predicament of the person you support. I often used to tell myself I shouldn't be happy when Kathryn was so sad and sick. But you can't help or motivate others if you feel negative.

It's not easy, but it's OK to carry on as normally as possible. Sometimes it's frustrating, and it can feel as though life is passing you by, but here are a few tips:

Study by correspondence. I finished a management qualification in between showering and other duties!

Take a break, go for a walk, or visit a cafe at a funny hour.

Enjoy a wine. Perhaps have one while cooking dinner.

Get help if you need it, and tell people how you feel. It's funny: you lose your privacy sometimes, but that's part of your new role. You're sharing the care now.

Don't neglect your kids. It gets pretty heavy some days, so always try and be friendly. Don't have a short fuse!

Get involved in school things like galas. It's odd if you're the only male around sometimes, but it can be a fun distraction.

Have a holiday! Don't be shy about going fishing, sitting by a lake, or just blobbing out for a week. Don't feel guilty.

Accept the hugs from others. I am a cold frog and don't come from a huggy family. But it's possible to loosen up. People really do care you know!

Sadly, Kathryn passed away suddenly in May. We offer our condolences to Hamish and Ian, who asked that his story be published to help other carers and their children.

Care + Children

Ensure there are plenty of hugs and holding hands so the physical bond continues. You can tell them to show how strong their handshake is (without crushing the poor person if they are frail)!

People often don't talk about the fact that after strokes and brain injuries an affected person can react in an unusual manner that is out of character. I have always explained to my son that this behaviour is a side effect of the stroke, and to not take it personally.

In extreme situations, people need to realise that kids are very accepting and positive. Don't be surprised if the child wants to fly a Lego jet over their sick Mum or Dad! Don't hush them up or get stressed, just be watchful in case other residents or patients become annoyed. Otherwise, let it ride!

More Suggestions

School: Comments like "Mum would like you to do well at school" can be helpful. Don't get too over-anxious about disruptive behaviour from school age kids, but do inform teachers and the principal about your situation, so they know empathy is called for, and to contact you if they have concerns.

Finances: Kids can feel guilty if they are aware of loss of income after a family trauma. Just seek as much help as possible from available services. Let the kids come with you to learn how the Work and Income process works, and just how many forms need filling in! Tell them that you are getting valuable temporary help until you can go back to work.

As I write this, I have had to let go and entrust my wife's care to others.

Sometimes we do need to trust in others, which can be hard for steely, independent New Zealanders. This can be the biggest hurdle to cross, especially for men.

Life does not stop in these situations, but our duties and priorities change. The kids can get left out in times of stress, so do seek help from friends and family if possible.

This is a big one. Don't be a hero, and be sure to have breaks. It's OK.

I hope these ideas will be useful to others, particularly men who are new to caring for a spouse or other loved ones.