

ANGELS IN GUMBOOTS

Useful information for farming carers
caring for those with memory loss

by Jennifer Evans
in association with

FCN | THE FARMING
COMMUNITY
NETWORK

Foreword by The Farming Community Network

For those working in farming and living in rural communities, dementia can have serious and potentially devastating effects.

When a person is living with a dementia-related condition it can have a significant impact on their ability to farm successfully. Dementia can seriously alter behaviour, memory and competency and has an impact on working patterns and physical and mental ability. There are also safety concerns on farms as they can be very hazardous environments for the person living with dementia.



For those living in rural communities, dementia can exacerbate feelings of isolation. It can present difficulties accessing healthcare services, transport and other amenities and it can be a challenge to access information around dementia and other conditions. When caring for family members with dementia, tending to the farm and looking after the business can be a heavy burden to carry alongside your caring duties. You may struggle to see how you can possibly keep the farm business operating and you may not know where to turn or who to ask for help.

If a loved one has dementia and you are struggling with the upkeep and management of your farm, The Farming Community Network (FCN) can help. Our volunteers understand the pressures of running a farm, and we can talk to you about options, help you to prioritise what needs to be done and provide you with a sympathetic voice and listening ear during this challenging time.

We hope this booklet will be of use to those caring for people with dementia whilst maintaining a farm, as well as signposting individuals towards the help that FCN can provide.

- Dr Jude McCann, Chief Executive Officer, The Farming Community Network

Introduction

This is the story of a farmer's wife whose husband developed dementia, and is a quick list of how to begin to get things running smoothly, to give the space to do the all-important caring.

I wrote this in fits and starts as my husband's dementia was obviously beginning. He had always run the farm, the accounts, and all the negotiations with supermarkets - we had been cherry tomato growers on a small farm of 30 acres, selling pre-packed direct to supermarkets. I had been tomato-planter, cook and bottle-washer, rather scatter-brained, hence my habit of constantly making notes.



I had to rapidly sharpen up to priorities only, and I knew nothing about finance, or how to keep the farm maintained, and least of all: how to run everything, while caring for my increasingly worried husband.

I found I had two patients: my husband, and the farm. I desperately needed to find out specifically how to respond to him in his new persona, while keeping him happy and loved. And at the same time, the farm was now visibly falling apart with buildings needing repair – which farm crisis to deal with first?

These notes are a quick guide and a starting point, remembering what I needed. I hope that some of the answers - an assemblage of all the notes I wrote to myself - might provide some useful information which was not available when we were going through this.

It is broadly written for any carers, but particularly for carers in a farming situation. It is also for GPs, to have something positive to give to new carers when they are reeling from a probable diagnosis, and it is for Carer Support Groups when they are composing their contact lists and the queries from carers.

- Jennifer Evans



Contents

Page

5 - 6	Angels in Gumboots
7	Dementia Carers - Wish List
8 - 9	Checklist for Carers
10	Help and Support
11 - 12	Dementia Tips
13 - 14	Ideas for Visits to the Care Home
15	Year Calendar

Angels in Gumboots

Two years ago my dear husband was clearly getting dementia. What I needed urgently was an angel, wearing gumboots and not too many floaty garments, to come through that farm gate and tell me what to do.

There was no way my husband was going anywhere near a doctor, he was angry and frightened, and no way that I could find out how to respond to this new “him”. The farm buildings and fences round our 30-acre farm were doing what farm buildings and fences do: they gently collapse and fall down. No fence means no farm. This is the nightmare time called the SILENT GAP. It was before we could get medical help, but too late for the rusting barn, the water leaks and the spinning water meter, the hanging gutters, the lights that didn't work, and only just in time to get a Power of Attorney signed.

At last we got him to see our doctor, and traipsed round the medics. They provided an onslaught of pills, and the County Council Carer Support group caused contact lists to rain down from heaven...but still nothing on how to respond to my new husband and keep him happy, and absolutely nothing on farms or where to start or which crisis to deal with first.

This SILENT GAP is the last and most valuable opportunity for gathering knowledge, there is even time for going on courses when my husband could safely be left. Knowledge can be found in books. I have now found three books that are essential reading for new dementia carers:

- *Contented Dementia* by Dr Oliver James. It contains all the knowledge and experience of different cases to help you learn how to respond to him (ISBN. 978-0-09-190181-3).
- *Compassion with Dementia* by Hilary Cragg for well set-out wider advice (ISBN. 9781914 288180).
- *If Only I'd Known That* by Susan Hartnell-Beavis from The Leonardo Trust - it is a breath of fresh air to read (ISBN. 978-1-80049-496-1).

Books can be scribbled in, highlighted, notes written in, and you can find your way with Contents and Indexes, and read them without the patient resenting you spending time at the computer screen. Carer Support need urgently to emphasise BOOKS as the most practical sources for dementia carers, online is not the panacea here for many people.

The SILENT GAP is a time of great anguish: your lovely capable husband (or wife, or parent), who has always run everything, is suddenly mortal, and struck down with this terrible disease, they are angry and frightened, even dangerous, and it is all suddenly down to you. There is so much you need to know, NOW.

However, most crucially, there is a silver lining - few people realise that Carer Support can be asked for before diagnosis. As soon as you realise that something is not right with your husband, wife or parent, you can ask for support and information, no need to wait to see your GP, just get on with it. There is so much help out there, not solely medical, if you ask the right questions.

And one of the right questions is: what ELSE is worrying you, apart from the dementia? It may well be finance, or it may be some area that your partner has always dealt with and now cannot or will not, but it is vital to identify to yourself that there is another big worry and to find who to ask and how to solve and reduce this extra burden.

A FARM is a classic example of this, it is your home, it is all around you, and it needs constant upkeep. The Farming Community Network are at the end of the phone. They can be contacted on 03000 111 999 or help@fcn.org.uk and the charity is ready to listen and support, and if necessary to provide knowledgeable Angels, definitely in gumboots, to come and help you with working out which crisis to deal with first.

If something good can come out of my family's disaster, I wish that this early access to information during the SILENT GAP could be generated throughout the whole country, not just county by county, and for every farmer and farming family to be assured that Farming Community Angels do exist, and do have gumboots, and are here to listen, support and actually help you.

Dementia Carers - Wish List

The best information opportunities are:

1. Right at the beginning: The only information at this stage is medical, when you first take the patient to the GP and then later to a Consultant. Carers are unaware that they can ask for Carer Support to assist them before a diagnosis. This is the time when only family and close friends realise that something is amiss. Sometimes there is a Community Mental Health Nurse who might be notified, and who could provide these summary lists to every carer: this booklet, and the essential reading list of books highlighted on page 5.

2. Carer Support: Many contact lists can lack information about farm help. The Farming Community Network (FCN) can be contacted on 03000 111 999 or help@fcn.org.uk. Carer Support needs nationwide links.

3. Books: In addition to online information, books should be listed for carers and emphasised. Books can be taken away and read, and notes written on, and important bits highlighted. Three essential books are listed on page 5.

I should love there to be a Care Package containing all this information for every carer as soon as anyone in the GP practice, or any of the clergy, or the family, hears about a new dementia patient.

And the main opportunity for carers to learn everything they possibly can about dementia is during the SILENT GAP before official diagnosis, when the patient is still independent and able to be left, while the carer could go on a course.

It is no good offering courses or health checks too late in the progress of the disease - courses of many weeks' duration and too far to drive while leaving a vulnerable patient on their own in the house. As soon as the patient hears the diagnosis, they are in a state of shock and despair; that is not the moment for the carer to leave them to go on a course. I believe everything at the moment is in the wrong order.

And this help, and information lists, should be available nationwide.

Checklist for Carers

House Check

- * Council Tax - apply for reduction, citing dementia
- * Electricity/gas
- * TV licence
- * Insurance
- * Broadband & phone line
- * Heating/boiler service, check heating-oil level
- * Water, pay bills. Identify and label stop valves

- *Computer* - antivirus, internet
- *Power cut* - check main trip switch, phonenumber, fridge and freezer
- *Spare keys* - especially Yale-type. Never shut door unless keys in your hand!
- *Filing system* - expandable file for carer forms, Sharpies for lists, red clothes pegs for bills. To start with: 3 big cardboard boxes (finances, farm, whatever, until you can get accountants and advisers to help)
- *Accounting system* - ask for professional advice, keep A4 cash book or use spreadsheet on computer to keep a record.
- *Digital clock* (showing day & date)
- *Small re-writeable noticeboard*
- *Back-up important computer files*

Car Check

- * Service
- * Road tax
- * MOT
- * Insurance
- * Tyre pressures

- *Oil & water check*
- *Fuel*
- *Check car ownership (V5 log book), and car insurance, are in your name*

People Check

Health checks - keep a log, check pills and re-order prescriptions, dentist, optician (get spare specs), chiropodist

Watch for reaction/side-effects to new pills and tell GPs immediately about any changes.

Set up Lasting Power of Attorney (Health and Welfare and Property and Finance) - DO THIS EARLY, before you need to be a carer. Get both Wills done EARLY. Check that all Deeds and Land Registry are in both your names.

- * Driving licence
- * Passports
- * Senior Railcard
- * Bus pass

Finance - bank accounts (check Standing Orders & Direct Debits), cards and cheque books.

Direct Debits - check that any important Direct Debits e.g. electricity supply, are in your own name. Check that every single bank account recognises your Power of Attorney.

Farm Check - fields and buildings

- Check animals and their water every day
- Buildings: secure? Waterproof? Implements? Tractors?
- Fences, hedges & gates
- Grass: need to cut/eat off/let grazing/sell?
- Water: check meter weekly on recycling day; check ball-cocks
- Find/make map of water pipes, electricity, oil, broadband, drains
- Electricity: read meter to check against "E" (estimated) on bill

* Insurance - must include Employer's Liability and Public Liability if the public go on your land (e.g. footpaths). Check with solicitor.

* Accounts - assemble and submit, or do online, by 30 September each year

* **Mark dates on the Year Calendar included on page 15.**

Help and Support

The Farming Community Network (FCN) is a voluntary organisation and charity that supports farmers and families within the farming community through difficult times. FCN runs a confidential national helpline (03000 111 999, open 7am-11pm every day of the year) and an e-helpline (help@fcn.org.uk).

Apply for Attendance Allowance. Citizens Advice / Age Concern will help with form.

Ask for Carer Support early from your County Carer Support Team. Ask for the Carers Emergency Plan form and make sure you fill it in so you are ready for if your partner needs to suddenly go to hospital / a care home.

Ask friends for help, and ask for recommendations - you will need to find:

- 2 carers who can do sitting service
- solicitor, accountant specialising in agriculture
- farm adviser, tech adviser
- builder/handyman, electrician, plumber
- mower lawn, mower grass, fencer, scrap man



Dementia Tips

I have been carer for my husband for two years, he is now in a dementia care home, and I think much “happier”, certainly more relaxed as he is no longer “boss”. It is no use just applying common sense where dementia is concerned; it is a new ball-game, you have to re-learn everything. These are a few suggestions which I hope will help others in a similar situation:

- *Get your family involved* - they'll be working or studying, but must be there for you and their parent/Grandma/Grandpa. Emails, texts, whatever; you need someone to communicate with. Also, find an area in which your partner can still help, so that they feel valued and useful.
- *Keep a log, or diary.* This is essential - later you may have to produce evidence or a record of episodes that they need when assessing whether you can get grants or which level of Attendance Allowance. Get a professional to help you fill in the Attendance Allowance form (e.g. Age Concern, Citizens Advice).
- *How to respond to this new person* - you the carer may have to completely change your habitual demeanour with the patient. It takes practice but it really does help keep things calm and manageable. Avoid direct questions. Don't contradict, never say 'I've already told you'. Never say 'do you remember?' - instead begin 'When we went to Cornwall' or show a photograph.
- *Find a care agency who can provide a sitting service.* Start with friends “dropping in” to get both of you used to it.
- *Get a digital clock*, which tells you in large letters what day it is. It arrives already set up, you just plug it in.
- *Make a list of favourite stories from his life*, and later on you can use them to talk with him, when he's a bit hazy about them (family can help with this). If he gets delusions, write those down too, on a separate list, if only to cheer you all up, they can be quite funny!
- *Make a photo album* showing events in his life, the family at various stages, holidays, dogs, friends.
- *Write a biography or timeline of his life.* This will help any carers, and staff at any care home, otherwise all they can see is a man in a chair.
- *Get a daily pill-sorter.*

- *Try and get any appointments done early* (dentist, hospital, chiropody etc.). There may be many hospital appointments, for all sorts of different parts of the body, as the body is saying: "there's something badly wrong here, but don't know what it is".
- *Get an A4 cash book* to keep a rough track of income and expenses, pensions and direct debits. You may have several bank accounts to run.
- *Find locals who have experienced this in their family.* They will be your best help, and become immediate friends.
- *Get spare spectacles made* - insist at the opticians.
- *Get spare keys made before you lose them* - especially any Yale-type keys. Check coat pockets each time before you hang them up.
- *Earmark* somewhere out of sight where you can go and have a cry, or make phone calls (I had a glasshouse, and grew tomatoes in it).
- *Keep your plans well aired and ready to pick up again.* Don't lose hope! Order those books! And a highlighter.

No, I wasn't brave, you get used to it and as soon as a delusion moment starts it is very obvious he is away with the birdies, hatching it up, then when it hatches out, look out! I permanently had the house keys and mobile in my pocket, and would hot-foot it over the fields and gate to friendly neighbours. Or I'd take car keys, and go somewhere, anywhere. Because he wouldn't remember anything about it later. And I still love him when he's himself.

And I had the farm to run as well. I would like to spread the knowledge about **The Farming Community Network**. This is a vital contact to fill the SILENT GAP. This is the nightmare time when the wife and family know that he has dementia, then you have to somehow get him to see the GP which takes six months because he's frightened and cross, then you have to see a consultant and get the all-important diagnosis - another six months.

One vital piece of information is: carers can ask for help before diagnosis, even before seeing a GP. GPs can help by giving carers a Carer Package with contact lists of available help, on paper as well as online. The lists of Contacts are the routes to the advice and knowledge that you are hardly aware of yet that you will need. This is the time to gather knowledge while the patient is still fairly independent and able to be safely left. Don't let the SILENT GAP be wasted - during this time you can go on courses and acquire knowledge.

Ideas for Visits to the Care Home

- For visiting in the care home: two visitors work best, whenever possible. It can be more relaxing to be three people just chatting – so long as the patient is included in the chat. Slow quiet chat, not busy gossip, and not direct questions if possible.
- On one visit we had to sew on more nametapes (order 2 lots, as everything has to be named in a care home) and he loved it, the chat, and being with us. Latterly he has hardly been eating, so we have brought fruit, and one Bendicks at a time, which went down very well, was pounced on in fact! Or Roka cheese flaky biscuits.
- Grapes are wonderful to pick at, or a tangerine to peel. Out of season strawberries, just two or three. Or raspberries: a treat! And Ribena, or elderflower to drink, to have something to look forward to, and different, or fizzy drinks, if it doesn't produce wind!
- Photos make a trigger for a conversation or a memory, 2 or 3 photos on each subject. Have several subjects, because sometimes what you thought would be a merry subject produces a delusional idea going off at a tangent, e.g. the patient had to clear up the mess, or the ship ran aground.
- Vital: a notebook with his stories written down – he'll love these, especially as he knows the punchline, or what happens! These will eventually become gold, and will be his legacy down the family.
- One or two poems that he knows or at least will respond to. One that came to mind and saved the day was The Blackbird Song – a very Somerset song! He knew all the words and joined in!
- Short excerpts from TV sit coms with the special lines: e.g. don't panic!
- Favourite DVDs – make sure the relevant machine is working, often the remotes go walkabouts in care homes, and have to be anchored to their machine with super-glue and string.

- Favourite CDs - music is really loved by many people with dementia. They can move to it, and sing, and can remember the words which gives them huge pleasure and fun.
- Much earlier, when my husband was still at home, jigsaws were a great source of fun, especially simple wooden ones.
- Faith and belief are so important to people, especially when they have lost almost everything else. For those with a Christian faith, regardless of whether the local vicar can visit (and they should), programmes such as Songs of Praise on the TV tick two boxes for them: faith and music. Equally, a family member could quietly hold the patient's hand and suggest they pray together. They could say a familiar prayer such as the Lord's Prayer and ask for God's blessing on the patient. Depending on the patient and their ability to respond, you could ask for God's help or forgiveness for anything that is worrying them, and give thanks for everything that they have been given. Go carefully, watch their expression.

Other forms of prayer and reflection will suit patients of different faiths and beliefs. Importantly, reassure them that they are loved.



Painting by
Jennifer Evans

Year Calendar

January	July
February	August
March	September
April	October
May	November
June	December



Produced in association with
The Farming Community Network

Helpline: 03000 111 999
e-Helpline: help@fcn.org.uk

Copyright: Jennifer Evans / FCN (2022)
Cover photographs © Caroline Maggs

FCN | THE FARMING
COMMUNITY
NETWORK

