

The story of Karen's life: a summary

This case study is about a lady called Karen, who is supported by MacIntyre at a Registered Care service. Karen was born with Down's Syndrome. Karen has lived within MacIntyre for most of her life; she has one brother who is older than Karen and is actively involved in her life. Karen was diagnosed with Alzheimer's Disease in 2014. Since Karen's diagnosis, staff have done their utmost to provide the best possible support for her.

Karen's dementia diagnosis:

- Concerns from the current Head of Service at Karen's home began in 2013. A Consultant formally diagnosed Karen with Dementia on 1 April 2014.
- The Head of Service and the staff team, the Consultant, a GP, Karen and Karen's brother were all involved in Karen's diagnosis.
- Karen's brother visits her home approximately once a month. He will also visit if any issues arise that require discussion.
- The impact on Karen's life from living with dementia has been huge. Karen's communication now is just an occasional smile, a mimic of staff or saying "no". In terms of choice and control, staff have to use their knowledge of Karen to support her in making choices and maintaining as much control over her life as possible. Although staff have done their utmost to involve Karen in every aspect of her care and support, Karen doesn't appear to have insight or knowledge about what is happening to her.
- A key challenge has been the lack of access to a care coordinator or dementia specialist nurse who could have supported staff with information, advice and help with concerns as they arose and also with future-proofing Karen's care and support.
- Looking ahead, there are challenges around end-of-life care if Karen remains at her current address and staff are unable to access the support they need.

Significant factors that have enabled Karen to live well with dementia:

- Since Karen's diagnosis staff have done their utmost to provide the best possible support for Karen.
- The involvement of Karen's brother has helped to provide support and stability for Karen.
- Karen has benefited from having her own funding to buy items she has needed.

The Story of Karen's Life

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Alongside being born with Down's Syndrome, Karen was diagnosed with Alzheimer's Disease in 2014. Since Karen's diagnosis, staff have done their utmost to provide the best possible support for Karen.

Profile

Name: Karen

Age: 51

Where Karen lives: South/East Midlands

Type of support provided by MacIntyre:
Registered Care

About Karen

Likes, dislikes, hobbies and interests:

- Karen likes to have her hands and feet massaged with creams and to have lots of cuddles.
- Karen's favourite colours are pink and purple.
- Karen likes having her hair done with lots of hair accessories.
- Karen values time with her brother and his wife and likes them to visit her, or send her cards and presents.
- It is important to Karen to have routine and consistency.
- Karen dislikes formality and prefers people to address her in an informal/cheeky way, rather than by calling her by her name. This is a very important aspect of how MacIntyre staff have implemented person-centred care, using their knowledge of Karen and their experience of how best to communicate with her, in order for that communication to make sense to her. Strangers may find the communication between staff and Karen 'unusual' because they don't have this knowledge of Karen.
- Karen spends increasing amounts of time in bed, which is where she seems happiest and most comfortable.
- Karen used to attend a MacIntyre Lifelong Learning service, but due to her mobility problems and support needs, this is no longer possible. Lifelong Learning staff now visit Karen at home.

Karen's character:

- Karen has a wicked sense of humour and loves to laugh at a mishap
- Karen likes people who are cheeky and rude and will join in a joke with you
- Karen likes to care for other people, especially when they aren't feeling well
- Karen likes to look smart

Personal history:

Karen was born with Down's Syndrome. Karen has lived within MacIntyre for most of her life and lives with 5 other people. Karen is the youngest and has lived at this address since 1998. Karen has one brother who is older than her, but has no other siblings and her parents are now deceased. Her brother is actively involved in Karen's life. Karen has never been a very social person, although 2 years ago she had a friendship with Kelly at another MacIntyre service (Kelly is now deceased). Karen has since had an imaginary friend who is also called Kelly.

Karen's healthcare

A summary of Karen's health history and current health needs:

- Alongside being born with Down's Syndrome, Karen has been diabetic for most of her life (Karen has insulin twice a day) and was diagnosed with Alzheimer's Disease in 2014.
- Karen has historically been incontinent, is visually impaired and is deaf in one ear.
- Karen has Raynaud's disease (a condition where Karen's feet and hands are always cold), stomach problems (including cramps and constipation) and takes a statin for cholesterol management.
- Karen takes an antidepressant (prescribed because Karen was crying a lot) and sleep medication (melatonin). Karen also takes risperidone (an anti-psychotic – Karen has taken anti-psychotics for many years prior to her dementia diagnosis). In Autumn 2016, concerns were raised about the level of medication Karen was taking and the risks of poly pharmacy. Karen's doctor has since reduced her prescription of risperidone.
- Documentation suggests Karen has historically screamed to express herself.
- Karen has had two operations in recent years.

A summary of the concerns leading up to Karen's diagnosis:

- When the current Head of Service came into post at Karen's home in 2013, she noticed changes in Karen. The Head of Service had known Karen since 2005, and was aware that Karen's mum had dementia. This family history was a specific trigger for the Head of Service raising concerns about finding the cause of the changes in Karen.
- In discussions with the staff team, the Head of Service was briefed on their observations of the changes they'd noticed in Karen (incontinence and forgetfulness). However, staff felt that everything could be explained as 'Karen's behaviours'.
- When the Head of Service initially saw the Consultant about the concerns she had regarding Karen, the Consultant suggested the changes in Karen were related to her diabetes. Staff continued to monitor Karen, noting that Karen's blood sugars weren't high (high blood sugars could contribute to problems like incontinence).
- The Head of Service asked for another appointment with the Consultant, who put in place a 'Simon's Assessment'. Staff continued to monitor Karen, keeping detailed written records and returning for appointments with the Consultant. Changes seemed to happen quickly (within 6 months) and then Karen's symptoms appeared to plateau.

Karen's dementia diagnosis

Timescale:

- Concerns from the current Head of Service at Karen's home began in 2013. A Consultant formally diagnosed Karen with Alzheimer's disease on 1 April 2014.
- However, records show that Karen was admitted to a psychiatric unit from May-Sept 2005 for 'behaviours'. Upon admission, dementia was mentioned as a potential explanation for Karen's changed behaviours, and during her inpatient stay Karen attended a dementia clinic appointment which resulted in a psychology report that stated: *"some deterioration in Karen's level of cognitive and social functioning within last 6-12 months. Karen may be experiencing symptoms of psychosis. It is recommended that Karen's mental state be further examined. The outcome for MMSE would allow for ruling out possible psychosis in order to confirm dementia."*
- There is no further paperwork readily available until April 2010 when a 'Simon's Assessment' took place. 3 further 'Simon's Assessments' were then conducted in November 2010, November 2011 and March 2014.
- There are significant gaps in the paperwork and audit trail of Karen's health records, possibly due to archiving, which makes documenting an accurate timescale impossible.
- In addition, on discovering the 2005 inpatient stay information during a routine Dementia Project audit in early 2017, it was clear that the current Head of Service was not aware of this. The Consultant that formally diagnosed Karen had never mentioned this inpatient stay to the current Head of Service, and her predecessor had never mentioned it during the handover to the current Head of Service.

What worked?

The diagnosis meant staff could no longer put Karen's problems down to her 'behaviour' and 'Karen being Karen', just because Karen had historically had 'behaviours', incontinence and poor diabetes management.

Diagnosis was fairly timely once concerns were raised and pursued by the Head of Service.

What didn't work?

- Diagnostic process was not explained to staff.
- Staff had to fight to make their 'case' about Karen's problems and persuade medics to investigate.
- Staff felt abandoned and didn't understand what was happening.

Who was involved?

The Head of Service and the staff team, a Consultant, a GP, Karen and Karen's brother.

What tests were involved?

Karen didn't have a scan as Karen wouldn't have been able to tolerate this. Blood tests were possibly taken.

Karen's involvement:

Karen attended appointments and some health professionals visited Karen at home. However, Karen was very much viewed as a passive patient and not actively engaged in the diagnostic process. It was felt that Karen was never properly told what was happening and why, and her diagnosis was never officially told directly to Karen by the Consultant. The Consultant discussed Karen's diagnosis with staff in Karen's presence but didn't directly address Karen.

MacIntyre staff involvement:

- Attending appointments and supporting Karen at home and at the Lifelong Learning service.
- Documenting all information and taking it to appointments for discussion and raising concerns.
- Advocating for Karen and trying to change things to make life better/easier for her. The Head of Service and her staff team felt they needed to fight for Karen. Their view has always been that Karen is entitled to the same treatment as everyone else, yet because Karen has a learning disability staff feel that at times Karen was just dismissed.
- Trying to pick up Karen's trigger points when Karen would get upset and trying to maintain harmony within the household and ensure that the needs of Karen's housemates during this time were addressed.

Family involvement:

Karen's brother attends appointments with his sister, but more so since her diagnosis than prior to her diagnosis. Karen's brother knew that his sister was undergoing tests for dementia, but wasn't present on the day of Karen's diagnosis; although he did discuss the diagnosis with the Consultant. He also attends Karen's reviews with MacIntyre staff.

Who was present at Karen's diagnosis?

- Doctor (Consultant)
- Karen's Head of Service
- Karen's Link Worker
- Karen

What has happened since Karen's dementia diagnosis?

Healthcare offered:

- Follow up appointments with the Consultant; some requested, some automatic. However, when the Head of Service raised concerns with the Consultant in the Autumn of 2016 regarding the amount of medication Karen was taking and the risks of poly pharmacy - requesting a review of Karen's medication – the Consultant spontaneously discharged Karen back to her GP. This decision was later reversed and Karen remains under the care of the Learning Disability Specialist Psychology team.
- GP input, including an annual review with the GP, an annual medication review with the GP and a diabetes review with the GP every 6 months. For the last diabetic review, the GP visited Karen's home.
- The diabetic nurse visits twice a day and Karen has her feet cared for by a chiropodist.
- Karen had a seizure a few months ago and was taken to hospital by ambulance. Karen was discharged without admission and Karen has no official diagnosis of epilepsy. Karen is awaiting a brain scan. Due to mobility issues, Karen's scan appointment was postponed.
- Speech and language teams have visited Karen twice. Oral thrush is affecting Karen's swallowing and this is being treated. All of Karen's food is puréed.
- There has been no dietician input. Karen's weight is generally quite stable, although constipation has been a significant problem for Karen in recent months. Karen's constipation has been extremely uncomfortable for her.

Adaptations to Karen's support:

- Karen moved to a specially adapted downstairs room in the latter part of 2014. Work was carried out, funded by the local authority, to convert the office to Karen's bedroom and a toilet became an en-suite shower room for Karen. Concerns about Karen's mobility prompted the move to the downstairs room – Karen is visually impaired and with her dementia diagnosis this seemed the safest option for meeting Karen's needs at the time and into the future.
- Karen has bought her own profiling bed and chair in the lounge. If Karen didn't have her own funds, it would have been more complex to obtain these items and the Head of Service would have had to try and source funding from MacIntyre.
- Soon after Karen's diagnosis staff bought crockery and cutlery that is designed to assist people who are living with dementia. Staff have also bought a blender for puréeing food and a transparent cup to monitor Karen's fluid intake.
- A swivel seat to help Karen get onto the bus was purchased but is no longer used.

Training and support for MacIntyre staff:

The team supporting Karen have attended Dementia Special Interest Group (DSIG) meetings, utilised the MacIntyre DSIG training pack and dementia e-learning, and had support from Beth Britton, MacIntyre's external dementia consultant (non-medical). Beth's visit to Karen's home in April 2014 triggered the creation of Karen's memory box, as well as environmental adaptations and a renewed emphasis on staff training in dementia care and support. As Karen's mobility has declined, The Head of Service and a senior member of her team have had key manual handling training so that they could then deliver training to the rest of the staff team, as well as hoist training in early 2017.

Karen's involvement since her diagnosis:

Although staff have done their utmost to involve Karen in every aspect of her care and support, Karen doesn't appear to have insight or knowledge about what is happening to her. When new items have arrived (her bed, hoist etc), there has been no reaction from Karen. Staff continue to involve Karen and communicate with her, reassuring her as things change.

Involvement of Karen's family and peers since her diagnosis:

Family: Karen's brother visits her home approximately once a month. He will also visit if any issues arise that require discussion. When Karen's brother visited recently Karen was in bed, and her brother found this visit very difficult as Karen was unresponsive. Karen's brother is also consulted regarding spending Karen's money – her chair cost over £2000 and this type of spending required his approval. Karen's brother also attends appointments with Karen.

Peers: Karen's housemates 'visit' Karen in her room. One housemate seems particularly concerned, although this may be down to Karen's crying keeping him awake. He asks every morning how Karen is, as does another housemate. No other peers or friends visit Karen or have any contact with her.

What has worked?

- Primarily actually getting a diagnosis of dementia for Karen.
- Karen's diagnosis has motivated staff to put whatever they can in place for Karen to help her to live well. They have done lots of research and sourced items to try and help support Karen.
- The way staff work with Karen is very heart-warming. Many staff had no prior knowledge of dementia so Karen's diagnosis has been a big learning curve for them. Staff are very empathetic - there is a lot of love for Karen.
- Karen's brother is 100% behind both the staff and MacIntyre and has been very supportive throughout the diagnostic process and beyond.
- The support received from the DSIG has been very helpful.
- Beth's involvement, visiting Karen in 2014 just after her diagnosis of dementia and again in 2016 and 2017, as well as providing remote support via email, including writing to Karen's GP when Karen was unexpectedly discharged by the Consultant in Autumn 2016.

What hasn't worked?

From Karen's perspective:

Karen's lack of involvement, as well as the prolonged diagnosis timeframe. Whether early dementia symptoms were missed or masked, Karen's diagnosis was delayed and took away her chance to live well with her dementia for longer with more knowledgeable support.

From Karen's family's perspective:

Missed/ masked symptoms that potentially delayed Karen's diagnosis, and a lack of information from medical professionals. After Karen's diagnosis, Karen had an NHS Continuing Healthcare Assessment. The CHC assessor said to Karen's brother, "*your sister will most likely be dead in a couple of years. She will be moved.*" This was undoubtedly very distressing.

From MacIntyre's perspective:

Staff felt they could have been given more guidance, support and advice throughout the diagnosis process and beyond, especially in terms of future-proofing Karen's care. There are many times that staff struggle, questioning Karen's symptoms (particularly screaming and crying) wondering, "Is this behaviour?" "How far has Karen's dementia got?" Staff have fought for everything that has been provided for Karen.

Treatments offered – both medicine and non-medicine based:

- Karen is taking memantine for her Alzheimer's Disease. Karen was originally prescribed Aricept but she didn't respond well to it. The Consultant authorised the change in Karen's Alzheimer's medication.
- No non-drug treatments have been offered or tried.

How have Karen's other health needs been addressed/included?

- Karen has always had extensive diabetes management and this has continued.
- Karen has had medication for a variety of other health problems.
- Medication has been provided for symptomatic relief of distressing symptoms for Karen. However, no other less-invasive options have been offered.
- There is no named health coordinator.
- There is no liaison between learning disability and dementia services. The Memory Clinic wouldn't see Karen as she has a learning disability; the only service available to Karen was the local Learning Disability Service.

The impact on Karen's quality of life

- The impact on Karen's life from living with dementia has been huge. Karen was "a feisty tornado who ruled the house" - the life and soul of her home. Now Karen can't do anything, not even swear (which Karen used to do regularly).
- Karen's communication now is just an occasional smile, a mimic of staff or saying "no". There is no other communication.
- In terms of choice and control, staff are having to use their knowledge of Karen to support her in making choices and maintaining as much control over her life as possible.
- Karen has deteriorated rapidly since her diagnosis. Karen has had prolonged periods of crying and screaming, and demonstrated behaviours that have caused her considerable distress and created difficulties for her peers. Karen is now very sleepy and has lost her mobility.

Significant factors that have enabled Karen to live well with dementia:

- Since Karen's diagnosis staff have done their utmost to provide the best possible support for Karen.
- The involvement of Karen's brother has helped to provide support and stability for Karen.
- Karen has benefited from having her own funding to buy items she has needed.

The role of health care and social care:

- Healthcare professionals have conducted assessments and prescribed medication.
- Karen's social worker has secured extra funds for Karen's support.
- No other social care providers have been involved in Karen's care. If Karen leaves her current home her new accommodation is expected to be within MacIntyre.

Key challenges

- Karen's health history (including concerns about dementia dating back to 2005) not being referred to throughout Karen's pre and post diagnostic life with dementia. Either Karen's history wasn't known about or wasn't mentioned.
- Being denied access to the Memory Clinic and having no continuity with GP care.
- No access to a care coordinator or dementia specialist nurse who could have supported staff with information, advice and help with concerns as they arose as well as with future-proofing Karen's care and support.
- No access or support with treatments or therapies aside from medication.
- Without her own funding, Karen potentially wouldn't have had essential specialist equipment at home, such as her bed and chair.
- The attitude of NHS CHC assessor also presented some barriers, as did Karen's spontaneous discharge from Specialist Learning Disability Psychologist in Autumn 2016.
- Difficulty obtaining a medication review when concerns were raised about the risks of poly pharmacy in Autumn 2016.
- Looking ahead, challenges may arise around end-of-life care if Karen remains at her current address and staff are unable to access the support they need from local healthcare professionals.

Assumptions made/ prejudices demonstrated:

- Staff have often felt their concerns have been dismissed because Karen has a learning disability.
- Too often excuses have been made or other conditions used to mask what was the development of Karen's dementia.
- Assumptions have also been made by healthcare professionals about Karen's level of understanding and capacity to understand important information relating to her healthcare, most notably when the Consultant never directly told Karen her dementia diagnosis.

What does the future hold?

Staff have always wanted to keep Karen at her current home provided they could cope with Karen's symptoms, particularly her screaming and emotional outbursts.

However, discussions are underway for Karen to possibly move to another home within MacIntyre that provides nursing care. This would be to future-proof Karen's support, with it being likely that Karen will need more nursing care in the future.

If Karen does move, staff and housemates at her current address will find this very difficult to cope with as Karen is a much loved and valued housemate.

If the move happens, Karen's current Head of Service would go with Karen to her new address for the first week to support Karen.

End note:

Following the completion of this case study, Karen has now moved to a MacIntyre nursing home in a neighbouring county. The transition was carefully planned. Karen's brother remains very actively involved and she is linked into a new network of health professionals.

Contact details:

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