Falling through the social care net

A personal story about a failing system and how we could change it.

By Rachel Way

30th October 2020

Our team at Public World partnered with Buurtzorg to found Buurtzorg Britain and Ireland for a reason: because we believe that the way in which Buurtzorg has transformed care at home in the Netherlands should inspire and inform a much better way of doing things in Britain than our current system can offer.

We also believe in sharing stories that help demonstrate the values and beliefs that underpin our partnership with Buurtzorg, and that is why I thought I would share this one.

When I joined Public World and had my Study Visit to Buurtzorg as part of the TICC project, I remember thanking the nurse teams I met in the Netherlands with my entire being, for showing me how their approach makes an incredible difference to the people they care for.

In the back of my mind, I could see my Grandparents sitting at home in their chairs with little or no contact with anyone from the health care or the social care systems. The people that were a part of their community had passed away and that left only the family to pop in and see them when we could.

But they wanted us to see them in the same way we always had. They didn't want to become a burden to us, or to be seen as a patient or a pain or a task.

Mrs Mason

My grandmother passed away two years ago now and to this day I believe that she could have lived happily and more healthily for a few more years if the social care system, beyond the family, had been able to anticipate and try to prevent later problems.

She was a strong, stubborn and brave person. In her seventies she fought off a 16-year-old girl with a knife who was trying to mug her. The bruising she sustained was significant, but she held on to her bag with all her might until she finally slipped on the curb and had no choice but to let go.

Over the last few years of her life she developed dementia, but we had not fully realised how severe that was because she was so quiet and made no fuss and never told us anything she was worried about. The ulcers on her legs did mean that a nurse might come in now and again when they were at their worst. No-one seemed to build a relationship with her though. She was never on the doctor's radar, she didn't pop up on a system somewhere that said, Mrs Mason is in her 80s, maybe we should check in on her.

Don't get me wrong, as a family we tried. We tried a lot to get her some help, we tried to convince them they needed a downstairs bathroom. We wanted carers to go in once a day to check she was up and bathed and dressed each day. But that is not what they wanted.

When my Uncle who lived with them, and was their sole everyday carer, needed a heart operation of his own, I knew instantly we would need to put a lot of things in place to try and prevent an incident happening during his time away.

It was during this time that my grandmother had a fall that led to a hospital visit and because she was in such a bad way it was decided a care home was best for her. The system then fought over whose responsibility she was financially.

It wasn't a case of Mrs Mason needs some care and attention and let's find the best way to help her live a happy life. It was, well she doesn't have enough medical needs for her to be the NHS's problem, but she was going to cost the social care system too much for them to want to look after her either.

"It was a horrendous emotionally scarring meeting and I couldn't be more pleased she didn't understand."

Eventually she had another fall in her care home, broke her hip and sadly passed away a month later at the age of 95.

Mr and Mrs Mason (centre) with Rachel (to Mr Mason's right) and other family members.

Bring things forward to now. A global pandemic sweeps the planet and we go into lockdown. Along with so many things, the doctors' surgeries close to patients, appointments for everything are cancelled and I can feel it happening all over again.

Mr Mason

There is no way that my Granddad was going to get through this without at least one major incident.

He is 95, still goes to the shops, still wakes his son up for his breakfast which he has prepared each day. It is only recently he has needed to stop driving. He has had prostate cancer for 15 years and bladder cancer for the last three. He does not suffer dementia and has his full mental capacity.

He has had a couple of falls since March and been in hospital twice with dehydration. He does not drink enough because it is hard work getting up the stairs to go to the toilet.

During the pandemic, he, like many others, had appointments cancelled, including his foot checks for his diabetes, and by October (six months later) no one had followed up with him. No one had checked that the loss of feeling in his feet had not progressed.

Then, on a Monday a couple of weeks ago, he fell backwards, banging his head and hurting his back, and he was in a lot of pain. So he called the GP.

The first call to the doctors was a telephone consultation because there is a Covid risk, and he was told to take paracetamol. On Tuesday, he called again and was advised to try codeine. On the third day a doctor did visit and prescribed Codydramol. On Day 4 Grandad was taken to hospital where they discovered two compression fractures to his spine and no blood flow in one of his feet.

> **I'm not telling you this for sympathy or effect, or to complain about any particular individual or decision by professionals who are doing their best at any particular moment to manage competing demands and risks. I am telling you this to demonstrate the way our system is working (or not) and to share a belief that there is another way that might have prevented what happened.**

There have been many, many indicators for our systems to identify Mr Mason's particular vulnerabilities as someone who needs some extra care both in a traditional sense but also in ensuring he has a life that means he wants to stay well. But our systems are not designed to help until a potential problem becomes an actual problem, and sometimes that can be too late.

So how differently would Buurtzorg do this:

1. Like other Buurtzorg teams, the team I visited in the Netherlands build relationships in their neighbourhood, with all sorts of community groups as well as with GPs and others in the formal care system, and these contacts can highlight someone who might need support. A visit from a nurse for a cup of coffee and a chat can be the beginning of an assessment, and on second visit the same nurse might provide some treatment for some dry skin or help wash up whilst learning more. They build a relationship with Mr Mason and he starts to feel that he matters and is heard.

2. The nurses look at the whole picture. Not just the person who they are speaking to but the condition of their homes, how that person is managing with access and cleanliness. Does the house need some work? Are they keeping their clothes clean? They would listen to what matters to Mr Mason and start to paint a picture of the kinds of support needed and how best it can be provided, not necessarily by Buurtzorg itself, but perhaps with the support of the family, neighbours or others in the community.

3. The Buurtzorg nurse (let's call her Carola) might identify that Mr Mason really gets something out of talking to her and that he might be a little lonely. She can then look at which community groups he might like to attend. Perhaps a coffee morning that some other gentlemen in their eighties and nineties attend. Somewhere Mr Mason can tell his war stories and laugh with others of his own age and ilk. She might arrange for someone to pick him up and take him there.

4. Carola is still attending because Mr Mason really does need more help than he realises or wants and she has noticed that he seems quite incontinent because of his bladder cancer and needs some extra help to keep bathed and clean or that his clothes need washing and might call in the help that is needed. She learns that his grandchildren don't visit as much as he'd like, and she can start to encourage Mr Mason to invite them over.

5. Carola can highlight back to the surgery that Mr Mason doesn't appear very stable on his feet and that he could do with some extra support. He appears to sit in his chair all day and would benefit from some strength building exercises that the local day centre offers.

6. She can also notice that the stairs could do with some extra handles and there is no downstairs toilet.

7. She will know he was in hospital over the weekend for not drinking enough and will encourage him or note that an extra drop in later in the day might help.

Prevention and Cure

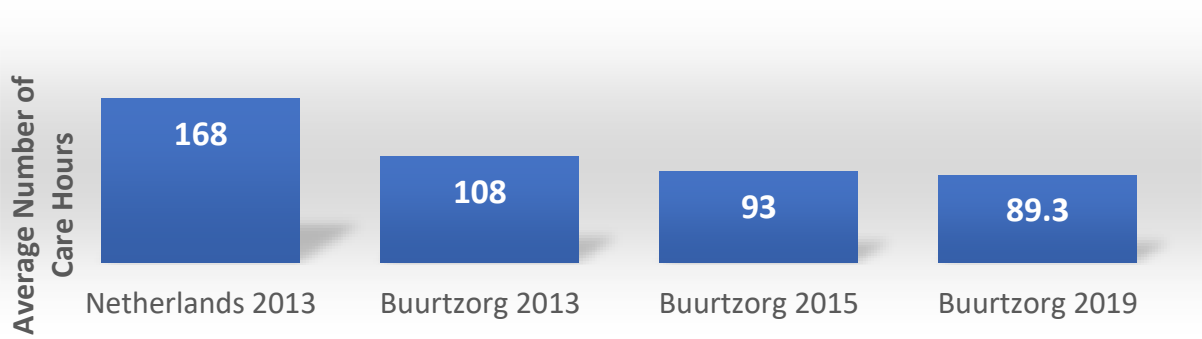
I hope you can see a picture developing of how this approach can support a person in their home. It might keep Mr Mason's strength up or mean that things are noticed earlier. It is these preventative measures and small tasks early on that will hold off the bigger issues.

No one is saying that Mr Mason will never fall over and fracture his spine. But it might help keep Mr Mason fitter and healthier for longer, thus making it less likely his fall is so severe and painful.

"The quality of his life would certainly be better, and he might feel less like his life was just about sitting in God's waiting room."

The economic debate

You might be thinking, this all sounds great but if there's not enough money to pay for the inadequate social care system we have how on earth could we afford what I am imagining. But the thing is that it works out cheaper as well as better, as Buurtzorg has shown in the Netherlands, because Mr Mason and many others like him need less care over time, which can also mean fewer doctors' appointments, fewer visits to hospital.



Through no fault of their own, those who work in our systems, who show considerable care, empathy, sympathy, respect, and logic for the most part feel there is little they can do to change things.

"My family's story is not rare, it's how our systems currently work."

They are given an amount of time a day and a list of visits to make. The times are set for them. It has all been planned for them without any conversation with the person needing support.

We need the Buurtzorg model of care and nurses like Carola, who is not given a short time slot to deliver only the care that is written down, and is trusted to do what is needed and make her own decisions, and does not have to rush because Mr Mason needed a toilet break in the middle of the care being provided.

The results would speak for themselves, Mr Mason would be better looked after, Carola would feel more fulfilled and happier, the care package would be fit for purpose, and if we were in that place well maybe we would keep more of the trained nurses and carers in the roles they trained for.

Postscript

This week my Grandad was discharged from hospital with a six-week 'reablement' care package. Maybe next week I will let you know how that is working out.