

Case 36: Walter

Social, cultural and historical context

Walter, aged 72, is single and lives with Christine, introduced initially as his 'niece' (though not actually a blood relative), along with her partner Phil, and their four children (aged 14 to 5 years), in a four bedroomed council house in a deprived inner city area. Walter has lived with them for 14 years. He spent part of his childhood in a children's home, then was fostered out at age 15 and followed his foster father into the army for six years. Subsequently, he worked on train maintenance and has also been a long distance truck driver. He has never married but he has two children that he rarely sees.

Walter's experience of ageing and ill health

Walter has chronic obstructive pulmonary disease (COPD) as a result, he thinks, of his lifelong smoking. He says he used to have home oxygen last year for the COPD but the nurse told him he didn't need it because his oxygen levels were OK. Walter disagrees with the nurse's assessment. He said he feels he needs oxygen sometimes. He uses an inhaler sometimes (but not, apparently, regularly) and a nebuliser.

He has prostate problems that have led to urinary incontinence, for which he wears pads. Walter says he can go for a couple of pints, go to the toilet, and then still find himself 'leaking'.

While Walter says, "*I don't have any problems, memory wise*", Christine explains that he does have memory problems (for example, he naps for an hour wakes up and thinks it is the next morning), and he also has vacant periods for reasons that are unclear. He is waiting for an appointment for a brain scan. Walter's sleep is very disturbed. At night, he sometimes wanders about the house and tries to cook. This is not safe (he has burned toast in the past), so Christine has put a lock on the kitchen door.

Walter is on various medications, tablets and inhalers for the COPD and more tablets for the prostate problem. He has regular visits from health professionals and is somewhat confused about these. On one research visit, he comments that two nurses had just been "*to see if I was all right*". He doesn't know why they came, though he does recall that he got a letter to say they were coming. Christine says they were from the pharmacy and they were here to check his medication – a new scheme recently introduced locally. They were pharmacists, not nurses. Christine says that last week, someone from social services came by to see how Walter was getting on and ask if there were any problems, though (Christine says) she could see there weren't.

Christine relates the time, about three years ago, when Walter had a severe chest infection and they put him in an induced coma for 6 weeks whilst his body recovered from the infection. They put in a tracheostomy and then woke him up slowly. She says he hasn't been admitted to hospital in the last 12 months but has outpatient appointments there.

People in Walter's life

Phil has been Walter's official carer for the last two years and Christine is officially his next of kin. Neither Christine nor Phil have paid work. Apart from Christine, Phil and their four children, Walter's main link to people is the local pub. There are also lots of animals in the house. There is a Staffordshire Bull terrier, a Jack Russell puppy, several rabbits in the yard outside, and five cats.

Walter is not in touch with his blood relatives – he has not seen his brothers and sister since their mother died 20 year ago.

What matters to Walter?

Walter's current adoptive family matter a great deal to him. He has been living with Christine and Phil since before their first child was born. Christine says, *"I think the most important thing for Walter is that he's got his family around him. You know, someone here for him. Other than that he doesn't really bother. If he was on his own, I don't think he would be here now. I mean obviously we have our arguments, our moments, but we get over it."*

Walter spends most of his time sitting in the house watching TV. Several times a day he goes out into the yard or to the front of the house for a cigarette, though he finds this difficult in the cold because it affects his breathing.

He likes to sit at the dining table. He says, *"I don't really bother much doing anything"* but that *"I like going out when I can"*. He acknowledges that he is somewhat slow in thinking of things and lacks motivation, *"You've got to catch me when I'm interested"*. He says he used to read, though he can only recall one book he read (Adrian Mole, and he says he doesn't read any more because he *"got fed up with it."*

If Walter goes out, it is usually to the local shop or the Working Men's Club over the road for a pint of beer. He would like to have more money (he dreams of winning the lottery), and if he had it, he says, he would do much more, especially travelling. As a former rail employee, Walter has a pass that gives him free rail travel. He says he could walk to the local station and from there he could go *"anywhere"*. The researcher asks what stops him doing that, and he replies *"Nothing really"*, but he has not travelled anywhere by train in recent years.

Walter's oxygen mattered to him as it relieved his breathlessness, but the oxygen was withdrawn on the basis of some readings taken by nurses. *"In their wisdom, they decided I didn't need it anymore and took them all out. And I used to go to a care centre as well and they used to put oxygen in the care centre for me."* This was an Age Concern care centre where Walter went twice a week. He stopped going because they introduced charges. He used to take money for his lunch, and if he had not had a bath Christine would ask them to do it and it cost £5. A few months ago, after he had been going for about a year, they said they would start charging him £15 a day. He misses the day care centre a little, but he had begun to find it slightly stressful because *"the bingo used to get on my nerves."* He has heard about a new day centre for people with COPD and is keen to try that.

Walter went into respite care for two weeks a few months ago, to give Christine and family a break and to give Walter a change and the opportunity to talk to other people. He was rather bored there and wanted to go out for a walk, but was not allowed to because of his memory problems. He says he might like to go back for another visit sometime.

Technologies in Walter's home and life

Walter has had the telehealth equipment for about a year but he does not use it now and nobody has been to collect it, though he and Christine say they would be willing to persevere with it. The devices include an oximeter, blood pressure monitor, thermometer and weighing scales. He still has a nebuliser, which he uses occasionally.

Walter says that someone talked about him having a pendant alarm but it didn't arrive. He had fallen 3 or 4 times in his bedroom and he didn't know what had caused the falls. He would very much like to have a pendant alarm.

Walter walks with a stick. He also has a bath seat (which he finds very useful), and the house is fitted with stair rails. Social services also put in a downstairs toilet.

Walter does not have a computer but Christine has one. Walter says he doesn't have a clue. *"I wouldn't like to get involved with [computers] anyway, I'm just not interested in them."*

Materiality and capability

The house has four bedrooms but it is small with a outside yard, and with 7 people and numerous animals, there is not much spare space. The nurses have talked about Walter having a wheelchair but Christine is not keen. There is no room in the house to store it. She also mentions the experience of her friend's father, who got a wheelchair and they now can't get him out of it. He gets no exercise and has put on weight. Walter does not feel he needs a wheelchair. What they would really like is for the council to put a large gate on the back yard fence so they can get the car in, making it easier to get Walter into the car, especially on cold and rainy days. The back of the house goes straight on to a car park so access would be no problem.

A major practical issue for Walter and his adoptive family is his incontinence. Christine says that the incontinence pads cost £13 per pack and Walter sometimes goes through 2 packs per week. This is a significant drain on the family finances and they are trying to get them on prescription. They are waiting for another assessment by the nurses to see if they are entitled to get them free. Christine says she was supposed to measure how much urine he passed but she didn't manage to achieve this. She explains:

"Last time, the nurse said, 'Write down what he drinks, how often he drinks it, how many times he goes for a wee, see if you can measure his wee', and I'm at it 'You're joking aren't you, I've got four kids in the house, I can't be running in and out of the toilet when he's peeing'. Then when I wrote it all down she said 'no, not good enough, he's not entitled to them.' It got to the point where he was leaking on to the couch and they're telling me he's not good enough, you know what I mean?"

Walter has very little energy. In a typical day, he has his bath about lunchtime and sleeps in the afternoon because he is tired as a result of being awake a lot in the night. He says repeatedly that he would like to get out of the house more but the combination of his memory problems, his incontinence and his low energy levels seem to combine to preclude this option.

Christine thinks that Walter needs sleeping tablets, *“because he’s up and down all night”*. She says if he slept better at night, he would be less tired in the day. Walter says his GP doesn’t like prescribing sleeping tablets, but Christine feels the GP does not really understand the lived experience of Walter’s illness: *“It’s like I said to her, she’s not here watching him all the time like I am”*. She describes Walter sometimes going into a “daze” and wandering about the house, especially at night.

Real incidents of using (or choosing not to use) an ALT

Walter gave up using the telehealth equipment because the times of taking the measurements were not convenient for his family. Walter needed Christine to help him take the measurements, but because of his sleep disturbance, he did not get up until late morning – by which time Christine was up and out of the house. They only used the equipment about six or eight times in total. The researcher asks whether the telehealth equipment was useful while he was using it. He replies there were lots of health professionals coming and going. He thought the point of the telehealth equipment was to save health professionals time but, he says, it didn’t seem to.

Comment

Walter’s case illustrates how the social determinants of health – including poverty, unemployment, overcrowding, low health literacy and smoking – underlie and exacerbate many of the problems of ageing and multi-morbidity. Whilst Walter’s blood family do not support him, his adoptive family are extremely devoted to him; Christine and Phil have made a number of key adaptations to the house (such as the lock on the kitchen door) to ensure he is safe and well cared for, and they are doing their best to navigate the (somewhat hostile) system to prove Walter’s eligibility for the services he needs.

Like many other cases in our sample, Walter has multiple medical problems that combine to produce the combination of low energy, low motivation and limited physical and cognitive capacity. Importantly, the very conditions for which he needs the assistive technologies make him incapable of using them, mainly because of their *non-specific* effects on his energy and motivation. His medical conditions are neither stable nor fully diagnosed (his vacant periods, for example, may or may not have a neurological origin).

Walter’s case illustrates that telehealth relies on the person’s own ability to use the equipment or on the ability and willingness of their family and friends to help them do so. Far from being ‘plug and play’, allowing remote monitoring of the individual whatever their capability and motivation, the technology makes high demands for cooperation and conformity. If the family routine does not mesh with that of the telehealth service, the

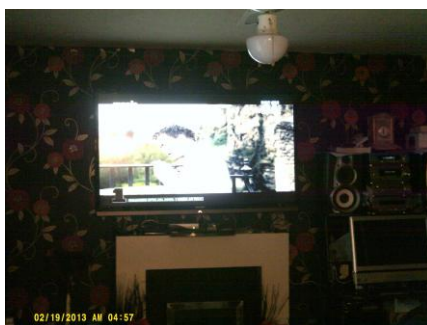
technology quickly falls into disuse. A question arising from this particular case is why, when the patient and his carer are both willing in principle to continue using it, there was not more effort on the part of the service to accommodate the family routine.

It is deeply ironic that Walter has been equipped with a telehealth package costing several hundred pounds (which he cannot use because the routine for sending the readings does not align with the wider routine of the family), but has been classified as ineligible for the simpler and cheaper solution of incontinence pads on prescription. The formalised assessment process, involving “objective” measurement of the amount of urine passed with a view to categorising Walter as either “needing” or “not needing” incontinence pads, contrasts with Christine’s account from the subjective perspective: she knows Walter intimately, and can describe from a subjective, “lived body” perspective how the incontinence affects him and the rest of the family. This example illustrates a more general phenomenon in contemporary health care – “objective” measures of health status using standardised instruments and checklists are invariably privileged over subjective, idiosyncratic accounts from the patient or carer.

Photos



Bath seat stored in his bedroom as his family need to use the bath



Plasma TV in his family lounge

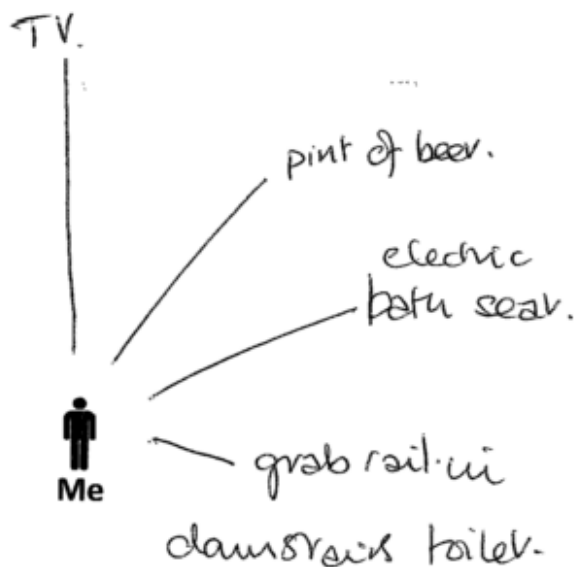


His bedroom

Home and Life Scrapbook Materials

Objects map

TV; Pint of beer; Electric bath seat; Grab rail in downstairs toilet



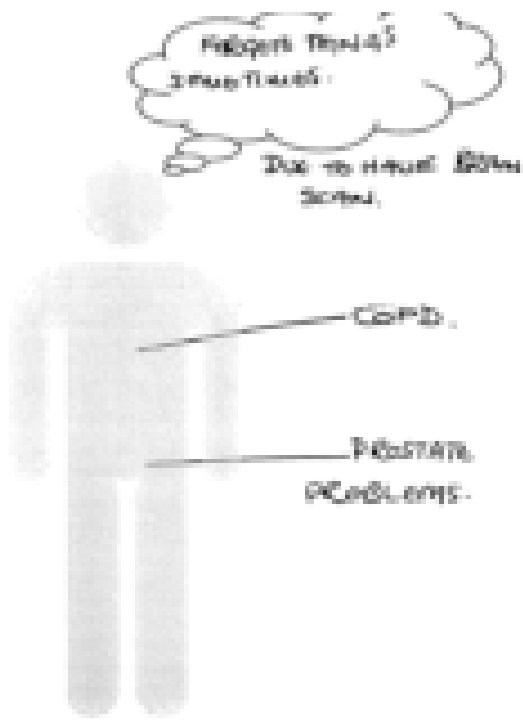
Likes and Dislikes List

- "Going out when I can"
- "Going to pub - beer."
- "Money - when I've got it."

Likes:

- Going out when I can
- Going to the pub - beer
- Money - when I've got it

Body Outline



Forget things sometimes - Due to have brain scan

COPD

Prostate problems

Places Map

chair at dining table in lounge.

Chair at dining table in lounge

bedroom.

Bedroom

pub.

Pub



Ma