

Cases 26 and 27: Colin and Anne

Social, cultural and historical context

Colin, aged 82, lives with his wife Anne, aged 85, in a 3-bedroomed flat in a large block of council flats. They have four children. They have lived in their current (rented) flat for about 40 years. Colin grew up in two different orphanages and went into the army for several years, serving mainly in what was then Malaya. After this he worked in the Post Office, first as a postman and then progressing to a senior supervisory role. He retired at 60 but then got a job as a security guard. He was on his feet a lot but he enjoyed it because it gave him something to do. He finally retired fully at the age of 75. Anne worked at a telephone exchange, also progressing to a supervisory role. She was made to retire at 60 but found many activities to participate in, for example various women's organisations.

Colin and Anne's experience of ageing and ill health

Colin has Parkinson's disease and arthritis of a number of joints. He had a knee replacement five years ago. He has cervical spondylosis (neck arthritis), gout in his big toe and high blood pressure. He has pain in his right leg and swollen feet with dry skin on both lower legs. He has also had cataract surgery. Shortly before the study he had been in hospital seriously ill with septicaemia, during which time Anne was in a nursing home (she had been admitted to hospital for a serious chest infection, then spent a year in a nursing home before returning home). Colin uses an in-dwelling catheter and urine bag as a result of kidney failure and bladder problems.

Colin has had a number of falls but none this year. If he did fall over, he wouldn't be able to get up again. Since discharge from hospital, physiotherapists visit to supervise his exercises and mobility practice. He uses a rollator frame when alone at home and practises with a walking stick with the physiotherapist.

Anne has memory problems and (currently) a pressure sore. Colin has played a key role in Anne's care for the past few years, for example doing the cooking. At the start of the study, Anne was again in an acute hospital. Colin had found her in the night, on the floor by the front door, bleeding from the head. She had fractured her neck of her femur and was admitted to hospital for an emergency hip replacement.

Colin was independent before his hospital admission, but since then, both he and Anne have care packages. Both have morning and evening visits, from different carers. Colin has help with washing and dressing his lower half, which he cannot do. He also has help putting E45 cream on his feet and fitting his compression stockings. Since Colin's recent discharge he has also had a lunchtime visit, just to make sure that everything is OK and he has managed to get food, but this is a temporary measure, due to finish soon.

Anne's care package provides help with all her personal care. District nurses should come every other day for Anne but they don't, so Colin and his daughter, Tina, have to chase them up by phone. These visits are vital due to Anne's sacral pressure sore.

People in Colin and Anne's lives

The most important person in Colin's life is Anne, and vice versa. He cares for her and she is his prime companion. Interestingly, when he draws a map of the people in his life, Anne does not appear on it. He explains:

"Well she's here yes, but she's not with it. Because she's not really involved, as far as this is concerned, she's basically just sits here really, being looked after."

Yet as the researcher observes, Colin is devoted to his wife and treats her with great tenderness, explaining things to her and tending to her physical needs 24 hours a day. He expended great efforts (and according to his family "wore himself out") visiting Anne twice daily when she was in hospital a year ago and daily when she was in the nursing home.

Colin and Anne have two daughters (who both live in London) and two sons (one of whom lives about 60 miles away and the other abroad in Europe). The main family support for Colin and Anne is their daughter Tina. She has several part time jobs but visits most days. Sometimes she comes early and stays till about 6 or 7 pm, other days she may not come till about 5.30 pm.

They don't see their sons much but keep in touch by phone about once a week, and the grandchildren visit occasionally. Colin says his children are all clever – all four have a degree and one has a PhD. Colin has several stepbrothers, some in the UK and one abroad, but they were separated in childhood, went to different orphanages and "we have never kept in touch". He has a sister in the USA who lives in a residential home. They phone each other from time to time, although it's a bit of a job getting through to her in the home.

Colin does not have as many friends as in the past. Two close friends of Colin's have died over the past couple of years, and the character of the local area has changed, making Colin feel more isolated:

"Well there was more, shall we say...people here who were more integrated than what the others do now like. ...The only time you see them is when you bump into them when you go out somewhere. Even my next door neighbour he don't bother much."

What matters to Colin and Anne?

Colin has not been out of the flat since he was discharged from hospital but talks about what he used to do – going to the park or to the shops to buy a newspaper or his favourite Cumberland sausages, or visiting the pub once or twice a week. He says the loss of walking ability is what affects him most.

"As I said, if it wasn't for my feet I would be all right. I told them in the hospital, I told them at the care centre, but nobody wants to know. Can't do bugger all I suppose."

Colin and Anne used to go out to various social events and clubs, for example a bingo night held at the local primary school. An old friend died a couple of years ago aged 94 and now Colin has no-one to go out with. Outdoors is now "too dodgy".

Colin cares for Anne at home because that's what they want. Even if he didn't have problems walking, he says it would be difficult to go out because he can't leave Anne on her own. He has had a letter from the Parkinson's disease support group but cannot go to the initial assessment session, which takes a whole afternoon, because he has to stay with Anne.

Anne spends most of the day sitting in her armchair, but Colin also tries to get her up from time to time to walk around a bit both for exercise and because of her sacral pressure sore. He makes sure she gets up slowly so she gains her balance. Colin sorts out all Anne's medication into a weekly dosset box and prompts her to take them. He helps her when she walks around at home, for example, going to the toilet and making sure she goes through the right door. If the evening carer is late he helps Anne get undressed and ready for bed. Colin says the arrival time of evening carer is very variable. Sometimes Anne doesn't want to go to bed when the carer is there, so Colin has to get her ready for bed then too:

"In the evening they get her ready for bed. Sometimes they get her to bed, but it depends. Last night I had to get her to bed, it took me about half an hour. Bloody nuisance."

Colin feels that all his days are the same now. The researcher asked how he felt about his social life:

"I'm quite happy, I've got what I want. I'm not one for going out much. So long as she's [Anne] happy I'm alright."

Having carers is quite new for Colin. He's happy with his enabler but he feels Anne's enabler is brusque and rushes, and Anne does not like her. Today the carer washed Anne down while she was sitting on the toilet, rather than going into the bathroom, because she was in a rush. Anne didn't like this, although she tells the researcher *"I do like my life"*.

Tina does the shopping. Colin is quite happy with this arrangement, as long as Tina is happy doing it. He has considered getting Tesco delivery to save Tina having to carry stuff, but he is in two minds – he prefers to see things himself or at least to delegate this to Tina.

Colin says that Tina often tidies and sorts things out when she visits. One bedroom is so full of *"collectibles from the last fifty-nine years"* that it is very difficult to enter. Tina is gradually sorting the things out, asking what Colin wants to keep or throw away. Colin says she has always been *"a great tidy-upper"* and sometimes he can't find things because she's tidied them away.

Colin is looking forward to a reunion event at the orphanage where he was brought up. He has arranged a hotel and a taxi to get there and back. It will cost him £150 each way but he is determined to go. His daughter Tina will look after Anne while he's away.

Colin really enjoys cooking and feels he is a bit of an expert chef. He also likes watching TV (*"if you can't go out, you've got to rely on the telly"*), reading books, and getting some fresh air. He walks along the balcony of the flats to the rubbish chute and looks over the railing to

see what is going on, who's there or not there. He loves the views from the flat and the beautiful sunsets. The security and familiarity of the flat is extremely important to Colin.

"You've got all your own things around you, like, you know. You haven't got to worry about where you're going next. It's all here, it's basically all here."

He tells a story of an elderly man who moved out of the block to a couple of roads away and was dead within a couple of months. Although it wasn't very far away, he didn't know anyone, so (Colin believes) he lost the will to live (*"He just packed up, gave it up."*). Colin draws an analogy with changing a budgerigar's cage – they die if you do this. Colin says what he likes about their flat is that it's comfortable, handy for buses, trains, shops and the church.

Religion matters to Colin. He shows the researcher his *Bene Merenti* medal, presented to him in 1986 by the Roman Catholic Church for long service. He plans to wear it to the orphanage reunion. He used to be a regular attender at the local Catholic church but he stopped going because they redecorated and (he feels) ruined it:

"It's more or less a station waiting room now, the way they finished it off. It had a beautiful altar there."

Technologies in Colin and Anne's home and life

Colin has telecare. There is a Tunstall control unit on a cupboard in the hallway. He was provided with a pendant alarm on discharge from the rehabilitation unit. He says his daughter suggested it and he agreed so she called the local social services and got it sorted. Colin always wears the alarm – it's the first thing he puts on in the morning and the last thing he takes off at night.

Anne has not got a pendant alarm, but Colin says he plans to ask for one for her. He has not tried his pendant yet, not even to test it. He thinks it will be useful because he wouldn't trust anyone else in the block with his door key, and this would save someone having to smash the door down. His daughters have key fobs to get past the security gates of the block. Colin seems to have a good understanding of what would happen if he pressed the alarm button. Tina is the first contact person if he presses it.

Colin has a Binatone mobile phone with large buttons and a big red button on the back, which dials his daughter Tina. He also has three telephone numbers, for his children and the porter's lodge at the block of flats, written on strips of paper taped to the back of the phone. The mobile was purchased by his daughter and son-in-law, to use outdoors in case of falls. It is pay as you go, which they top up for him. Once, when Colin fell outdoors and ended up in hospital, he was able to use the mobile to call Tina and let her know what had happened and where he was.

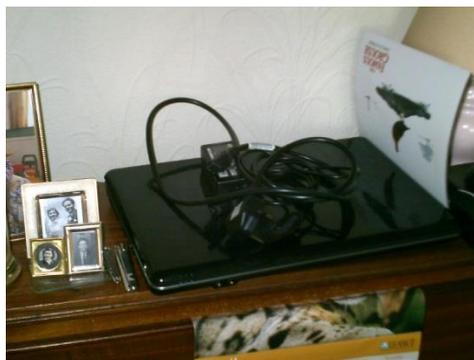


Colin's mobile phone

Colin has various assistive devices – a perching stool, bed raisers, bed rail, shower stool and toilet surround frame. Anne has a community bed and a 'high-risk' pressure mattress. Colin says these daily living aids are all very useful. He sits on the perching stool in the kitchen while waiting for porridge to boil or peeling potatoes. Previously he had to stand and got tired. He also has an 'easy reach', which he purchased himself, for picking things up off the floor, including the post.

Anne and Colin have a large flat screen TV. He thinks it's big but handy for seeing more of the picture. Anne has a wheelchair, which they purchased themselves. Colin says it is level access to the nearby park and he would like to be able to take Anne there, but they have not done this yet.

Colin has a laptop computer, bought for him by two of his children "*...but I don't use it. I'm not much up on them. These black boxes.*"



Colin's computer, a gift from his children

Tina uses the computer when she visits, for her own work or looking things up for Colin and Anne. She shows Colin what she is doing but he says he does not understand what is going on ("*You fiddle about with it, you don't know where you are.*"). Colin says there is Skype on the laptop, installed by his grandsons. The researcher asks if Colin would be interested in using Skype. He says yes if it worked ok, but he's non-committal. He does not think his sister in the US has the facilities to use it.

Materiality and capability

Colin can manage most things he needs to for daily life in the flat but he can't get outdoors. Although he still does some of the housework he can't now manage cleaning the windows, which open outwards. He used to clean them by climbing on the sideboard but his daughter has advised him not to do this.

His hand tremor makes it difficult to get dressed and shaved but currently he still manages these activities independently:

"Buttons sometimes are a bit of a nuisance...so I have to get hold of the button hole, and pull it open, so I can get the button in, or pull the button off and undo my shirt, that's the easiest way sometimes."

When asked if he has any ideas for technology that might help him, Colin says the only thing he needs is *"a new pair of legs, from the knees down"*. Colin dislikes using the rollator frame, which he calls *"that bloody thing"*. The researcher observed him walking backwards from the front door after picking up the post. This has a higher risk of falling compared to turning round in the hallway, but Colin says he does it because the hallway is narrow and it's difficult to turn the rollator around.

Colin and Anne have separate bedrooms, but he stays half-awake to listen out for her. If he hears her getting up, he also gets up. She's only got up a couple of nights so far since coming back home from the nursing home, but this keeps him awake:

"I'm not sure whether to go to sleep or not. I just lay there and any noise, I'm listening around, waiting to see if I can hear anything. I'll probably doze off, hear something else and be awake again."

Colin says he gets tired quickly nowadays and has little spare energy. The most important things in the flat for Colin are his chair and his bed:

"Because you can get comfortable in them and have a kip in bed. Or just have a lay down in the afternoon for an hour, half an hour, something like that, rest me tootsies."

Colin says one problem is if the (landline) phone rings while he is in another room, and he doesn't have time to get there. He has asked his children to let it ring twice, wait a bit and then call again, so he knows it's them and he's got time to get to the phone. His new phone has a long lead and if he goes somewhere he places it near Anne so she can answer it.

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

Colin has not had to use the pendant alarm for himself yet. When Anne fell in the hallway during the night he used the telephone to call for an ambulance and also his daughter.

Comment

Colin's case illustrates the difficulties of one unwell person looking after another, with the consequent physical and social restrictions on their lives and risk to safety. Worse, the situation is not static but may deteriorate. Colin, who is very tired from his efforts, is very accepting of this situation although he would love to get out more. Clearly, the issue is not merely technology requirements but the wider package of care – formal and informal – that will keep Colin and Anne together for as long as possible.

The reality of Colin and Anne's lives is one of gradually increasing physical and cognitive challenges, for most of which technology can do little to compensate. As Colin himself jokes, what he really needs is a new pair of legs from the knees down. But whilst their situation is difficult, it is their preferred arrangement, and Colin states that as long as Anne is happy and well cared for, he is happy too. Yet their lives could undoubtedly be made easier if the right technologies were in place. An arrangement such as sensors in Anne's bed linked with a vibrating alarm under Colin's pillow, for example, would allow him to have a more restful night with potentially beneficial effects on Colin's health and well being.

Like many other cases in this sample, Colin and Anne illustrate the phenomenon of boundedness – progressive shrinking of their social and physical world. It is increasingly difficult for them to go outdoors and, although they have lived in the block of flats for over 40 years, they have few friends amongst the neighbours. There are no easy technological solutions here. Rather, the fundamental issues are social and cultural ones.

This case illustrates the common phenomenon of technologies being brought into the home as gifts from relatives. Tina thought the computer (with wireless connection) would help Colin, but in reality he has not used it. This is partly because he lacks awareness of the potential of the computer to increase social contact, but also because he has very limited energy and motivation since so much of his spare capacity is spent attending to Anne. Tina is nevertheless an important asset to her parents, not least because she has taken to sorting out their accumulated possessions and gradually throwing things out. This contrasts with Geraldine (Case 18), whose live-in son Eddy is a hoarder of old furniture and broken technologies, to such an extent that much of their house is uninhabitable.

Photos

View from the window (photo taken by Colin)

A sunset taken from his armchair - He enjoys looking out the window and says there are great sunsets when there are clear skies.



Armchair and 'control centre' (landline telephone, remote controls, medication, cup of tea)

The most important technologies in the home?

"Chair and bed I suppose. Because you can get comfortable in them and have a kip in bed. Or just have a lay down in the afternoon for an hour, half an hour, something like that. Rest me tootsies."



Daily living aids: Perching stool, toilet surround frame, shower seat, bath board, bed rail

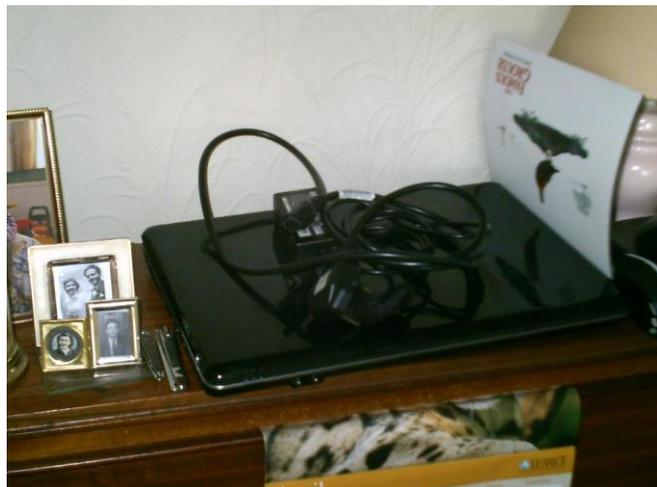
"I can sit on the perching stool while waiting for my porridge to boil or peeling potatoes. ... I'm going to cook fishcakes tomorrow."



Laptop

"I've got one of them things but I don't use it. I'm not much up on them. These black boxes."

"No [I don't use it]. I should do. I know I should do but, I've tried it a couple of times, just fiddled about with it. But whenever I want anything nothing ever comes up, so I just give up... She [Tina] showed me beforehand but when I tried it myself it seems to go all cock-eyed, so I don't bother. Just wait until she comes up."



Binatone mobile phone

He says the large numbers help because of his tremor and poor eyesight. The red button automatically dials his daughter Tina, and there are three other numbers written on the back.

"They told me to take it with me in case I had to call anyone while, if I fell while I was out."



Telecare control unit

Placed on top of a family heirloom in the hallway when he arrived home from a lengthy admission to hospital. His daughter had arranged installation. There used to be a large clock on top of this cabinet but Colin hasn't seen it since.

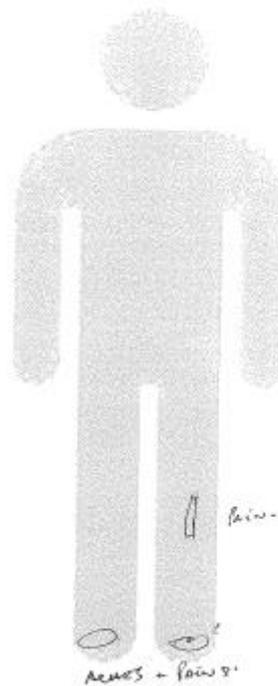
"The first thing I put on in the morning is this [pendant alarm]...till last thing at night. Unless I go out, then take it off. I don't need it when I'm out. ... This one is plugged into me. she [Anne] needs to get her own, she's got to get it plugged into her."



So

Home and Life Scrapbook Materials

Body outline (Colin)



Aches + Pains

'Comfortable with' and 'concerned about' list (Colin)

<p><u>I feel comfortable with...</u></p> <p>Carer's Being at home.</p>	<p><u>I am concerned about...</u></p> <p>Lack of visit by nurses. Wife's wanderings in head.</p>	<p><u>Comfortable with:</u> Carer's Being at home</p> <p><u>Concerned about:</u> Lack of visit by (District) Nurses Wife's wanderings in head</p>
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Wishes (Colin)

<p>1. I would like... to be able to get out a bit more</p> <p>2. I would like... people to visit, sometime.</p> <p>3. I would like...</p>

- 1) I would like... to be able to get out a bit more
- 2) I would like... people to visit, sometime

Diary (Colin)

Diary

DAY Saturday

Morning Kept awake most of night, wife playing about. kept getting out of bed. Eventually wet the carpet on the way to toilet, catheter playing up, disconnected 3 times during the night. Not much sleep.

Afternoon No visit by D. Nurse. Phone call waste of time.

Evening Carer arrived later probably owing to football.

Saturday

Morning:

Kept awake most of night, wife playing about. Kept getting out of bed. Eventually wet carpet on the way to toilet. Catheter playing up.

Disconnected 3 times during the night. Not much sleep.

Afternoon:

No visit by D(istrict) Nurse. Phone call waste of time.

Evening:

Carer arrived later probably owing to football.

Diary

DAY WEDNESDAY

Morning Nurse came again took blood and dressed wounds. Anne not so good. Talked to herself.

Afternoon Slept most of the PM after cutting a part of the table cloth. Anti biotic tablet got?

Evening Bed early for her.

Wednesday

Morning:

Nurse called again took blood and dressed wounds.

Anne not so good, talking to herself.

Afternoon:

(Anne) Slept most of the PM after cutting a part of the table cloth.

Anti biotic tablet got?

Evening:

Bed early for her.