

Tell Me More Report December 2021

1. Introduction

Tell Me More is an engagement project which aims to gather insights into the lived experience of care home residents during the Covid-19 pandemic and is funded by Welsh Government.

This report details key themes that featured in the conversations we had with people living in care homes during 2021, one of the most challenging times that care homes have experienced as a result of the global pandemic.

The report reflects the range of perspectives voiced by residents on care home life, through the restrictions that were in place because of regulation, guidance, or care home policy. It reflects the findings from conversation with 105 residents living in 22 care homes throughout Wales.

Care Homes involved Residents Welsh Speakers Care Homes	22 105 14 Glan Rhos, Anglesey Plas Gwilym, Penygroes Hengoed Park, Swansea Min y Mor, Aberaeron Duffryn Ffrwd Manor, Nantgarw Warrendale Cottage, Chester Llys Y Seren, Port Talbot Foxtroy House, Bridgend Willowbrook House, Cardiff College Fields, Barry Regency House, Pontypool The Cottage, Mold Hengoed Court, Swansea Coed Craig, Colwyn Bay Plasgwyn Nursing Home, Criccieth Hill View, Aberbargoed Sunrise, Cardiff Lyndell House, Swansea Woodland Lodge, Tenby Haulfryn Care, Wrexham Panorama, Cwmbran
	Panorama, Cwmbran Langton Hall, Fishguard



2. Connecting with care homes

Following the success of the initial Tell Me More engagement, some word-of-mouth recommendations and by using our care home data base, we were able to successfully in work with care homes to support them in using Zoom to connect with us. We needed to be sensitive and patient in our approach. By listening and learning from the homes, we knew that at times, our Zoom calls could not take priority in a climate where Covid was continuing to cause lockdown restrictions and staff recruitment was clearly a major concern.

3. Care Home feedback about the process

Care home managers and staff shared with us the positive outcomes that they saw from the project which include the confidence that residents have gained in using Zoom that have been applied in other situations and the opportunity for residents to engage with new people:

"The highlight was seeing the residents gain confidence on the zoom calls and for them to have felt not forgotten during the covid times" – Care Home Manager

"At first it was quite daunting for them (residents) as you (Age Cymru) were the first we had contact with outside of the home. You made the process very easy for them and it enabled them to take part in more zoom calls with doctors and families." – Care Home Manager

"The residents have thoroughly enjoyed the process of taking part in the Age Cymru Tell Me More project. Our artist Jon Ratigan made the residents feel relaxed and they found him easy to talk to. The residents enjoyed reminiscing and talking about certain aspects of their lives and achievements. They appreciated his time and his company" – Care Home Manager

"All residents taking part enjoyed the opportunity to meet a new friendly face and have their opinions and experiences listened to. They found it interesting that people were interested in how they were feeling in a Nursing Home, that they could see and speak with someone in Cardiff or another place. They were all mostly used to skyping with relatives, but it was a great opportunity to meet someone new and all appreciated being able to speak in their own preferred language, Welsh or English." – Activity Coordinator



Residents have also fed back about how they enjoyed the experience:

"Jon was a lovely man, very easy to talk to and very friendly" – Care Home Resident

"It was a great experience - please thank everyone involved" – Care Home Resident

"Jon was very nice, very patient and I am very happy with my portrait" -Care Home Resident



"Thank you, Emma. The portrait is lovely, and we would love a copy if you could send the same to us." – Family member

"The one-to-one format enabled Dad to think and respond more freely than he would have in a group. He was absolutely full of it when I saw him at lunchtime – he had a fabulous time (on Zoom) It was lovely to hear about it including some favourite stories and family memories I didn't even know – who would have thought that Dad enjoyed Eleanor Rigby by The Beatles! Thank you to Laura who obviously put Dad at ease and made him feel valued as an individual – a really great outcome. Thanks again." - Relative

4. Portraits

We used the same format as the pilot stage of the project, we recorded the residents voice via Zoom and recoding their faces in the form of 2D and 3D portraits. There is no doubt that the portraits were a real hook for the care homes to want to join in. Care home managers told us that it was so nice to be involved in an initiative which gave something back to the residents.

The residents were delighted with their portraits, they were very impressed with the likenesses and how quickly he (artist) managed to complete them. Some are planning to display them in their rooms whilst others will give them to loved ones to cherish – Care Home Manager



The residents said that they felt very lucky to have had the chance to take part and were proud to show the portraits and gifts to families, friends, and the other residents. Families were delighted by the project and that their loved ones had been captured in a way that is so original and lasting – Activity Coordinator

5. The Senses Framework and the 'Tell Me More' Project

Our guiding framework for this part of the project was the Senses Framework (Davies, Nolan, Brown, & Wilson 1999; Nolan 1997) http://shura.shu.ac.uk/280/1/PDF_Senses_Framework_Report.pdf

The framework identifies the senses that research indicates are experienced in the best care environments and we've used these to categorise the findings from our conversations_adapting it to meet the aims of the project and so we were consistent in our approach.

Security – to feel safe Belonging – to feel part of things Continuity – to experience links and connection Purpose – to have a goal(s) to aspire to Achievement – to make progress towards these goals Significance – to feel that you matter as a person

Some of the responses below are quotes directly from the resident, some are stories retold or reflected by the facilitator.

Theme 1 Sense of security – To feel safe

Attention to essential physiological and psychological needs, to feel safe and free from threat, harm, pain, and discomfort. To receive competent and sensitive care. Here was an opportunity to ask about the feeling of home and how that influences well-being.

Examples of some questions we asked:

Do you feel at home? What helps you feel safe? What would you change if you could?

What is the one thing people should know about you that helps you feel at home?



Findings

Residents shared with us how it felt to be living in a care home when the pandemic hit.

Facilitator: The resident I spoke with was blasé about Covid and said he was in the war and had to wear gas masks as a child, not able to go out etc., so to him this is just another illness that we will get through.

Facilitator: One resident told me Covid was hard in the home; she was diagnosed with it on Christmas day. They lost residents to the virus. She says Christmas day was not very nice at all, no presents, no visitors.

Facilitator: One resident said that Covid had not really affected her as staff all take precautions and she feels safe.

Hearing what was happening in the world was very important to some residents.

Resident: 'I cannot hear the news, but a friend rings me every night about nine o clock and she tells me what the latest is on the virus.'

Resident: 'I watch the news regularly and I talk about it because well obviously it is something that had to be discussed. I never missed the news of what the prime minster did say. I think sometimes it went in this ear and out the other. I always watch what is going on in the world because when the time comes when I cannot do it, it will be a different matter.'

Some residents told us that at times they found it difficult to find out what was happening in the outside world. Access to up-to-date information and guidance was often difficult to obtain. Some residents told us that they felt overprotected by staff who were wanting to keep them safe and away from news reports.

Facilitator: She told me that the staff keep turning the TV off to shield her from the news.

Resident: 'I wish they would have told me a little more of what was happening, because I would understand, and I'd keep my mouth shut and I wouldn't get frustrated then without being fobbed off'

Others told us about finding news reports difficult

Resident: 'I was terrified of the news reports about hospitalisation, as a chronic asthmatic.'



Everyone we spoke with told us that they had felt safe in the home where they live, they told us that care staff were working to protect them from the virus.

Resident 'We have to obey the rules here to keep us all safe.'

Facilitator: A resident had some advice on moving to a care home, she said that bringing something from your own home makes your care home room more homely.

Some residents however felt that this, at times, overtook their rights to make individual choices and restricted their freedom to make decisions that affected their quality of life.

Resident: 'It felt like a prison in here when you had to speak through glass doors, but it was necessary at the time. The first time you can get close to someone again was lovely.'

Resident: 'We were all confined to this place because nobody come in and nobody can come out. It was horrible.'

Resident: 'It has affected us in many ways because it is so warm in our rooms, they have taken the fans away, and the windows are only allowed to be open 2 inches.'

Some residents told us that staff had left their jobs over the last few months, and this was a real loss. Seeing care staff exhausted and struggling was also something frequently discussed.

Resident: 'I feel locked away and unhappy that staff I loved have now left.'

The unprecedented nature of the virus and the impact on the care homes we spoke with undoubtedly had an impact on the feeling of 'home' Residents told us things were not the same, the homes were quiet and lacked the usual sense of fun through activities and visits from loved ones.

Loss was a significant theme of our conversations. We have heard from residents who were aware of deaths in the homes where they live and within their own families.

'Deaths were around me, being younger I find it difficult to take deaths'

'It's like losing your neighbours.'



'I lost seven close friends'

'There is a hearse that comes at night for the bodies'

'I lost my wife and my sister to Covid'

Facilitator: She spoke about friends dying in the home and new people arriving, I asked her how this made her feel. She said that she always makes sure that she speaks to them (new residents) and tries to help them settle in.

We heard about other losses like changes in health, losing confidence and access to essential medical appointments and equipment.

Resident: 'I am getting a bit of cabin fever, it would be nice to go out, but at the same time, I am a little bit afraid of going out in the world because it has changed so much, and I would not know what to do.'

Facilitator: She told me that her cataract operation has been delayed due to Covid and she is worried about losing her sight. She also has a hearing aid, which she says needs adjusting. Therefore, she cannot see or hear very wellthis has led to her isolating from others and not being social despite being an inherently chatty person

Resident 'I feel the virus is being blamed for everything. I have been waiting for a wheelchair and keep being told it has been delayed because of the virus.'

Facilitator: She has lost a friend in the home and misses their conversations as there are not many Welsh speakers there, so she misses using her language.

Theme 2 Sense of belonging – To feel part of things

Opportunities to maintain and/or form meaningful and reciprocal relationships, to feel part of a community or group as desired. To be able to maintain/improve valued relationships, to be able to confide in trusted individuals to feel that you are not in this alone. Here was an opportunity to ask about friendships within the home and relationships with loved ones who visit.

Examples of some questions we asked:

What was it like during the pandemic? Did you make new friendships?



Who keeps you company? When you feel sad who can you talk too? How did you stay connected with your family? What do you miss? What was difficult and what could have made things better?

Findings

Residents told us how finding company during the pandemic was very important to them. Making new friends and maintaining good relationships came up in our conversations many times. We found that relationships with staff became more important than ever. Despite the barrier of PPE, residents often spoke of staff becoming 'more like family' their reason to keep going and the main connector for them with the outside world.

Resident: 'Just to ask you if there's anything you want, that's a big thing for anybody to be asked, people don't realise how nice that question is, you might not want nothing at all but you might and to be asked it and to be able to say- yes, really I'd like you to go across the road and get me a packet of toffees, like one does, it's lovely that cos, I love toffees!'

Resident 'The staff here are wonderful and take great care of us.'

Resident: 'I have many friends here, so I am happy; it is nice to talk to people.'

Resident: 'I get on well with the people with dementia. I know we cannot converse and have a good conversation but there are times when we can talk about old times.'

Facilitator: She told me about a friendship she had with one of the women in the home who she is known since she was a teenager. She said it is a very special friendship.

Resident: 'People are very rewarding...well the majority of people are. The pandemic was pretty bad, but I still found people to talk to here.'

Facilitator: Her friend in the home was also her friend before coming to the home and her next-door neighbour for many years.

It was difficult to hear that some residents who had a close relationship with another resident were sometimes kept apart due to living in a different part of the home and the Covid restrictions meaning that they could not see each other.

Resident: 'I'm here because I couldn't do a lot of things that I used to do at home. My husband is in the home too as well, the only thing is, he's on one part of the home and I'm on the other.'



Facilitator: He tells me he and his wife came to the care home in the summer of the first lockdown in 2020. They had been shown around on Zoom via an iPad before moving in. When they first moved in, they were in separate accommodation from one another due to Covid and couldn't see each other. "I had a difficult time, we arrived together...[but] my wife was on the first floor at the other end of the corridor." Once they were allowed, they began to visit each other's rooms for coffee and biscuits, taking lunch and dinner together in the home and going out on bus trips and visiting the garden. On their last trip to the garden, the magnolia tree was in bloom. "She saw it at just the right time..." His wife passed away in May this year after succumbing to her illness. "We had fifty- one years together."

One of the most talked about subjects we encountered was family visits to the homes. Some residents shared their sadness and frustration about this:

'It's difficult not being able to see people as you used to, that's the worst part.'

'I haven't seen close family for a year and a half. I feel insular. Covid just took my family away, without Facetime I would have gone crazy.'

'I've felt very lonely, although there are a lot of people here, it's not like having your own family, I've missed my boys coming in... now they can come in but not on weekends which is a bit silly, my one son can only make weekends.'

'I haven't been able to go out. We can see visitors in the garden and you're apart and you mustn't touch each other...What have the injections been for? that was a waste of time. If you had the injection, you should have been allowed to go out and see your family.'

Residents told us that they spent most of their time alone and in their rooms. They told us that they had little to look forward too and their days were long.

'I wish we could have more freedom, that it wasn't so manipulative, they keep you apart from your loved ones, it's very sad, my family were everything to me, it's been very hard.'

'You miss your friends and family because I know they have their lives to live but half an hour a week (visit) is not enough. There are 168 hours in a week, we get 30 minutes.'

Facilitator: He told me he has been in touch with his family throughout and has been able to see them through the window.

We heard from residents who told us their mental health had suffered because of the pandemic and restrictions to their daily lives.



Facilitator: Her care worker reported that since the Covid lockdowns, (resident) has started habitually pulling her hair out, she now wears a headscarf, 'I felt neglected, not wanted' she said. When her husband was eventually able to visit, she was short with him. Their relationship has now improved.

Resident: 'I love my family and I miss them terrible. I lost my wife and my sister all this year, it's been a terrible year'.

Theme 3 Sense of continuity – To experience links and connection

Recognition and value of personal biography; skilful use of knowledge of the past to help contextualise present and future. Seamless, consistent care delivered within an established relationship with known people. To maintain shared pleasures/pursuits. Here was an opportunity to ask about hobbies/interests, the past and future hopes.

Examples of some questions we asked:

What are your interests? Are you able to continue to do the things you love? Do you have opportunities to try new things? Have staff helped you to continue to do the things you love?

Findings

Keeping connected has been essential for the care home residents we spoke with. Some were not familiar with the virtual platforms before lockdown, so this had opened a new world.

Facilitator: She talked about how amazing SKYPE is. How technology allowed her to speak to family across the world. I skyped my niece in Canada... 'I thought that was wonderful...I thought you could only do that in Great Britain you know, I didn't realise you could Skype anywhere in the world, that's marvellous isn't it' she said she could even hear Niagara Falls!

Resident: 'Sunday morning at 10am my nephew chats to me through the window. Yesterday my other nephew put the family around the table, him, and his wife and his two children and they all had 5 minutes with me on FaceTime.'

We spoke with residents who were keen to share with us the activities that they enjoy.



Resident: 'It is great here; we have arts and crafts most days, almost every day. We used to have three arts and crafts teachers but because of the Covid, that is changing. However, we do have one most days of the week, which I love.'

At the start of this project, residents told us that the restrictions were a shared experience with the outside world but as the restrictions started to lift and people gained more freedom to socialise again, this became much more difficult for the residents. Some residents felt it unfair that families were meeting again, and they were unable to leave the home where they live.

Facilitator: A resident talks about his daughter's encouraging him to write to the First Minister about his experience of living through Covid in the care home and his frustrations about not being able to leave the home. Facilitator: They both (two residents chatting together) agreed that weekly family visits are good, but 30 mins are not enough, a decision that was not in their hands

A highlight for us all in this project was witnessing the change in the residents as families were able to visit again and some homes planned for the residents to go out again.

Resident: 'They (families) could come at one time once a fortnight I think it is started for half hour, and then it was weekly. Then it started that we could go out with our families'.

Facilitator: She told me she was 100 years old on Sunday and has had a wonderful few days seeing relatives and receiving cards and flowers from so many of her family and friends.

Resident: 'It has been lovely to see relatives again, it makes you feel energised!

Resident 'My son, daughter in law and daughter came to visit today and they were allowed into the bedroom – first time since covid stuck.'

Theme 4 Sense of purpose – To have a personally valuable goal(s) to aspire to

Opportunities to engage in purposeful activity for the constructive passage of time, to be able to identify and pursue goals and challenges, to exercise discretionary choice. Here was an opportunity to ask about independence and activity within the home.



Examples of some questions we asked:

Do you feel you are given opportunities to plan your own day with what is important to you?

What would you like to do/achieve before you get too old? What are you hopes for the future?

Findings

Residents shared with us how they were keeping active during the pandemic.

Facilitator: She said she is an avid gardener and misses her home, so the care home has given her own patch just outside her room window which she tends to. She has enjoys planting and seeing things grow; this has helped her in the last 15 months.

Resident: 'I like to read but I need quiet when I 'm reading so I can't be distracted'.

Facilitator: She told me she used to sing on stage. She sings in the care home now and then treated me to a song on Zoom, her voice is beautiful!

Resident: 'The only thing I'll be able to do now at the moment is... to grow the tomato plants in the greenhouse, we're doing chillies and peppers, somebodies getting some cucumbers to start'.

Resident: "I've done nine circuits of the gardens this morning, four or five before dinner and eight or nine after'.

Resident: 'I like to have a screwdriver and (do) all sorts of things.'

Facilitator: He has worked all his life and does odd jobs in the home to keep busy. He has made some good friends there.

Resident: 'I have been making scarves in lockdown; this is the fifth scarf I have made now!'

Facilitator: Talks a little about activities stopping because of Covid but was very enthusiastic about a Gazette newspaper, which families contribute to, and comes out every week in the care home.

Facilitator: A resident enjoyed telling me how she continues to knit and crochet and likes to live very independently.



Many residents told us that they found it difficult to know what to do with their days, many felt the effects of the loss of community engagement and fun activities.

Resident: 'I had six weeks on my own. I always thought that I'd enjoy my own company and do projects, but I failed completely. I don't read anymore, I use the TV quite a lot, but I can't watch what I want to watch, and I get angry. I'm a changed person now, I'm short with people and rude to people that don't deserve bad manners'

Resident: 'I did miss that one thing, because obviously you have your family and friends normally visiting. We used to sit outside and have a family get together but of course; I miss that because we could not do it.'

Facilitator: She told me all she does all day is think about times past, memories with the help of photographs. She likes to look at the clouds and sees pictures in them.

Some homes were clearly trying their best to keep spirits up. We heard about entertainers in the garden, new friendships forming in the homes and towards the end of this project many more activities taking place.

Theme 5 Senses of achievement – To make progress towards these goals

Opportunities to meet meaningful and valued goals, to feel satisfied with one's efforts, to make a recognised and valued contribution, to make progress towards therapeutic goals as appropriate.

Here was an opportunity to ask about goals for improved well-being.

Examples of some questions we asked:

What has been your biggest achievement in life? Do you set yourself goals to keep active? How does the home help you with this? Do you have any top tips on keeping well? What is the secret of a long life and happy? Where is the most wonderful place you know?

Findings

Residents shared with us what they had been doing to keep positive during lockdowns, some had continued gentle exercise in their room, and some had learnt new skills like knitting for example. We heard many stories of incredible resilience



and were privileged to hear some of the residents talk about their hopes for the future.

Facilitator: She was resilient in her response about pandemic 'there was no point in worrying, as it would change nothing.' She said was looking forward to road trips with her niece again.

Facilitator: She spends all day looking at the ceiling, her hearing has gone so she cannot watch TV, and she cannot really do much now but was smiling and full of stories.

Facilitator: He is happy in the home and his aspirations for the future is to be able to see the new road that is being built (bypass) and to be able to go out in the car with his family.

Facilitator: For her 100th birthday, she would like to visit her sisters down the road.

Facilitator: He has seen his family via Zoom including his sister and great niece who had just had a baby. He has now knitted a knitted a blanket for the new baby and looks forward to meeting the baby soon.

Resident: 'There are things you have in life and things you don't and there's no good worrying about it'.

Theme 6 Sense of significance – To feel that 'you' matter as a person

To feel recognised and valued as a person of worth, that one's actions and existence are of importance, that 'you matter'.

Here was an opportunity to dig a little deeper. The questions we asked were always in the context of the conversation, we took a go with the flow approach.

Examples of some questions we asked:

What is the thing that makes you the happiest? What do you look forward too? What don't you look forward too? How do you know when someone cares about you? What makes you get out of bed in the morning?

Findings

Some residents we spoke with had moved into the care home during the pandemic. There were positive stories shared.



Facilitator: He really struggled with lock down and he was in sheltered accommodation. His interaction with people got less and less, which made him depressed and lonely. He turned to drink, and he ended up in the care home for his safety.

Resident: 'We have been looked after; we cannot grumble. If I was home still, I would have to think about shopping, but I did not have any of that worry, because it was all put in front of me.'

Facilitator: After an illness he woke up in the (care) home, not remembering how he got there and having made none of the decisions himself. He has since accepted that this is his forever home and says he is well cared for and content.

And stories that were difficult to hear.

Resident: 'Unfortunately for me, we went into lockdown not long after I came in here. So really speaking, my life in this home has virtually been 90% of the time we've been in lockdown, Human beings are social animals and we're being kept apart from the people we love'.

Resident: 'I've had quite a few isolations and I can't get used to them at all. Now in the hospital, the nurses would come in, turn around and go back out as quickly as possible, never opened the door. Here, they've been kinder and had the door open, it seems a bit more human'.

Facilitator: He really misses his freedom, being able to go where and when he wants to.

Some residents told us that they had little to look forward to in their days. Illness or disability might affect their daily lives, but they were also experiencing delays in receiving essential equipment to assist them with mobility and/or sensory loss. The ability to move freely around the place they lived had an impact on their social and emotional well-being

Resident: 'It can be monotonous living here; I would like to travel.'

Facilitator: He has had COVID and said the staff did not tell him. He said he nearly died. 'I had it and I did not know I had it. They took me to hospital and told me I was going for a check-up and when I went to the hospital, they put me in this special ward. I was in there six weeks, since then my eating and smell has gone.'



Facilitator: If you had a magic wand what would you wish for? 'I'd like my eyes, if I had a choice of my leg or my eyes, I'd have eyes, I mean my one friend she lost her leg about the same time as me and I used to say to her, hurry up and get that leg healed and we'll go to town and we'll buy a pair of shoes and I had the right leg and she had the left leg and I said we can share a pair of shoes together and we used to laugh and.. she's one of the one's who died so we never did get our shoes...I think I'd have had a red pair! and I think she would have'.

Conclusion

Tell Me More has given us the most valuable insight to the lives of care home residents during the Covid pandemic. We've been privileged to be welcomed into the homes of the people who have been affected most by intermittent and extended lockdowns, continuous safety measures and restrictions and being separated from those they love.

Many residents told us that they had little opportunity to talk about themselves, their lives, and their hopes for the future. They told us staff were busy and there was currently a lack of opportunity to socialise through activities. Securing trusted relationships had also been difficult through Covid with staff recruitment and retention playing a part in some inconsistency within staff teams.

Tell Me More highlights the need for meaningful conversation in everyday life and how important it is for well-being. Through our conversations were made aware of

the isolation faced by care home residents and the lack of opportunity to contribute to day-to-day decisions that currently affect their lives.

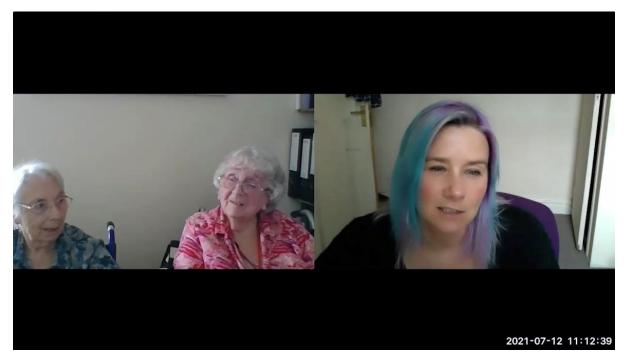
We have been privileged to follow the residents' journeys through Covid and have been able to listen unconditionally to challenges and frustrations faced. We have heard heart-breaking stories of loss that demonstrate incredible resilience. And we have been met with humour and hope even in the darkest of times.

A very special thank you to all the residents, activity coordinators, care home staff and managers who have worked with us to make this project a success.

A film {link} and conversation resource {link} accompanies this report.



Meet the team



Emma Prentice, Artist Practitioner



Sandie Grieve, Sector Engagement and Development Officer, Social Care Wales





Jon Ratigan, Artist Practitioner



Laura Reynolds, Artist Practitioner



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