MONSTER EXTRACTION

Inflight Report 3 - Butterflies

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MY POCKETS

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MONSTER EXTRACTION PROJECT
BUTTERFLIES MEMORY LOSS GROUP

INTRODUCTION

I am no stranger to dementia. Over the years, I have worked in this field many times, as a project manager, an evaluator, and a creative writer. At a personal level, I watched the illness slowly erode the memories of both of my parents until they died within six months of each other.

Ten years on, social care still seems largely focussed on the person with dementia, with carers not exactly taking a back seat but somehow expected to just *be* there, part of the system. So I was keen to learn more about the monsters project and its approach and impact, because here was something actually person-centred around the carer.

At a broader level, as well as gathering feedback on My Pockets, I also wanted to hear participants' thoughts about Butterflies. I ran a heritage project with them several years ago and have always had great respect for the work they do.

I began by joining two monsters Zoom meetings – one with the morning group and one with the afternoon – and then followed these up with 1:1 phone calls.

It was immediately evident from the Zoom calls that the carers, all women, greatly valued the chance to chat to others in the same situation. Peter and Sally were patient, allowing them to talk, yet always making sure they didn't get too off course. Everyone readily agreed to have a chat with me by phone, all asking that this be done after 4.30pm because of their many other commitments.

ONE TO ONE INTERVIEWS

I began by talking to Rachel, a carer in her late 40s, whose mum has dementia and is in a care home. Rachel herself has an illness that puts her in the 'vulnerable' category in terms of Covid-19 risk. She has been shielding in her mum's empty house for a year, whilst also having her own family back home, including a son in his late teens.

For Rachel, the monsters project had been "amazing … fantastic!" The key thing for her was having the rest of the project group to talk to about the issues she faced.

> "Although my mum's in a care home, it doesn't take away the stress of being a carer. It's quite unusual, having someone asking how you're feeling, like they [MP] do. So being in this group and just opening up to some of the emotions linked to that and the mental and physical strain of being a carer, it's been wonderful."

Here was food for thought straight away: caring was a 24/7 pressure, even when the person was, in effect, being cared for elsewhere. There was also a paradox. The monsters project invited the carers to rummage around in this dark topic, when you would expect them to be desperate for respite and escapism from it. Did the participants fully understand what they would be doing in the project? And yet, I thought, by openly discussing that 'mental and physical strain of being a carer', they were taking quite a risk – effectively flying in the face of the image of an angelic carer, tirelessly looking after their loved one. So perhaps respite came in the form of that rare opportunity to have an open discussion where nobody would judge them for being less than perfect?

Rachel had never come across a project like this before and "didn't know what to expect", but, although she was a bit apprehensive at first, thought she would "give it a go and see what it was like." Rather than run for the hills, she became completely engaged with it, and was particularly impressed by My Pockets:

> "The way their creativity has expressed what we've all said is … well … I'm just absolutely blown away by their creativity. It's been fantastic to watch, it really has."

Whilst shielding in her mum's empty house, Rachel has been slowly clearing things out. When the monster's project called for photos for the attic, she remembered she had taken her parents' wedding album to her mum in the residential home at the start of lockdown. However, she persevered and found a few albums from her childhood that had wedding photos tucked inside, so sent them through to Sally.

> "When my dad passed away, one of his friends came to the funeral with some photos he'd written on the back of, and one of them was a wedding photo of my mum and dad, so I sent that to Sally too."

The icing on the cake for Rachel was the inclusion of thimbles:

> "My mum collects thimbles, so Sally has organised them to be in the video for my mum. I think it's nice that they've done that, that they've asked us what would signify the person we care for. I thought that was really lovely, because it makes it really personal. Even though it's already personal because it's our thoughts that are being expressed in the song, I thought that was really nice."

This was now beginning to make more sense to me. Yes, the project was inviting the women to explore uncomfortable aspects of their lives and identify their monster, but, in doing so, it was also allowing them to connect with the person they cared for *as the person they used to be.* The wedding photos and the thimbles related to Rachel's 'real' mum. They were linked to her true identity. I checked in again on my own feelings. For me, dementia stole my real mum, causing her to say things that were extremely hurtful to me and, although I knew this was the disease at work, I still struggled to see it as anything other than that.

This led me to reflect on identity in the wider context. By caring for someone whose identity is gradually being changed/lost because of dementia, the carer was in danger of losing their own identity.

When it came to the song itself, Rachel thought it was "amazing" and we talked about the collaborative process.

> "It's a real catchy tune. I muted myself on the last call so that I wouldn't sing along! We had input into the words of the song, but Peter and Sally found a way of *expressing* what we were saying. And Jim doing the music was just … Well, it makes me so amazed, and to see people have such creativity, it's wonderful. And using it in such a good way as well."

What specifically, I wondered, did Rachel mean by "a good way"?

> "Well, it's definitely been a real good boost for me. One of the highlights of my week is that Zoom call and seeing what's happening and seeing our monster come to life through Mark's artwork and how he's created the puppet as well – it's just amazing!"

Like countless other people, I have had to come to terms with using Zoom for work. It was interesting to hear Rachel refer to it as one of the highlights of her week, because from an evaluator's perspective, I have found Zoom to be a mixed blessing. Helpful though online connection is, it can never take the place of physically being in that collective space with project participants. So, evaluating the monsters project I have missed the opportunity to read the room and observe reactions to My Pockets' usual spontaneity – the rummaging in boxes and bags, the dog-eared sheets of paper scrawled with Sharpie words, the 'organised chaos'.

I decided to explore this a bit more. Rachel told me:

> "It's a shame we're not able to do some of the activities. Peter and Sally have explained what they would normally have done … but no, it's been great. I do use video calls for work, so it's not been such a big shock to my system going on Zoom. And because it's a small group it's a lot easier to manage, there's not too many people trying to talk at once, which is good."

I could definitely see the benefits of people not all trying to talk at once. Conversely, I also mourned the loss of those little 'asides' that crop up when you are physically all together in the same space. When the evaluator is tuned in, these can often be the start of another interesting, valuable thread to pick up on. Such asides frequently come from people who feel less confident about talking to the full group. They are likely to be even more apprehensive about speaking on a Zoom call, knowing their face will fill the entire screen and the focus will be on them.

Moving on, I asked Rachel to describe the monster to me, because I hadn't yet seen it.

> "It reminded me a bit of Zig and Zag from the Big Breakfast show years ago. When I was a student, early '90s probably, I used to watch that. It's got big eyes. Really cute but really mischievous!"

Looking back on my personal experience of dementia and those of numerous service users and carers I had spoken to over the years, I was shocked by this monster's personality. Mischievous? To me, it had no redeeming features whatsoever: it was 100% cruel. So I was now keen to learn how this 'cute' monster had come about.

When I chatted with Dot, a member of the same group, she talked less about the monster, simply saying it was "real good" without quite knowing why, and more about the concept of the attic.

> "What we was trying to get was that with the attic you're in their mind. You've got all this jumbled up stuff and that's how their minds work … I think my husband's deteriorated that little bit more this year, being mostly locked up."

Dot and her husband have been going to Butterflies together for a couple of years. Like Rachel, she had never taken part in anything like the monsters project before and "was a bit dubious at the start, thinking 'ooh, what have I done!' It's all very different!"

Was she glad she'd taken the plunge?

> "I'll be honest, I'm really enjoying it. Now that I've done it once, I'd probably try something like this again. I'm not *that* brave though. They wanted me to be the bride for the film and I said 'oh no … no, no!'"

What was coming through was a sense of fun, a chance to play … a chance to acknowledge that being mischievous was actually acceptable, even when there was a dark undercurrent.

Dot and I talked more about the film and how she had appreciated choosing her own "bits and bobs."

> "My husband used to love his holidays. Always abroad. He loves the sun. We used to come back in September and book straight away again for the next year. So I chose some holiday photos. It's lovely to see them being used in that way."

As his periods of lucidity fluctuate, Dot wasn't sure what her husband would make of the monster in the attic – "if anything" – when he saw the film.

> “Sometimes he’s aware of what’s going on. He’s got other things wrong with him as well, but you never know what’s wrong with him, whether it’s the dementia or … He hasn’t heard the song yet. We’ll see how he goes when he does hear it.”

Dot herself agreed with Rachel about the song:

> “I’ve heard the music and the song and I think it’s lovely, it’s brilliant. It’s real upbeat.”

Given the topic, the reactions I’d heard so far put me in mind of a stone skimming a very deep, murky ocean. To some extent, even though the carers knew the song had come out of their discussions about such a serious topic, they seemed to see it as something separate – a lightness to counteract the dark. Perhaps this was another place where the respite came in?

Dot felt less ownership of the song than Rachel, with little or no reference to “we,” but she did fully appreciate the value of all the discussions. Rather than see it as a collaboration, Dot seemed to see two different things happening – they’d all had a chat and then the professionals had written a song. She referred to the lyrics in the passive: “The words are all done now and he was tweaking the music and what have you.”

I asked her what aspect of the project she’d enjoyed most:

> “It brings you out of yourself and you listen to what other people have to say. I’ve learned from other people. Sometimes they have their points of view that are different to what you have yourself. But you can say what you want and nobody worries about it.”

In my experience of having evaluated other My Pockets projects, this is one of the key ingredients of their success. They create a situation where, not only are people given permission to talk, but they’re in an environment where they can talk freely and without judgement.

Summing up, Dot felt My Pockets had “done really well, considering we’re not there in person.”

I then spoke to two members of the Butterflies team – Yvonne, who works for them, and Madge, who is a volunteer.

Yvonne explained that, as well as working for Butterflies, she had also had “her own dealings” when it came to caring for an immediate member of her family. Although she went on to share these with me of her own volition, she added that she had chosen not to bring the issue up in the group, preferring to keep it separate. However, she went on, in the monsters project “you think about that as well,” which had at times made things emotionally difficult for her. Nevertheless, she welcomed the opportunity for people to share the issues they faced.

> “The first sessions was getting to know each other and talking about what our monster was, the dementia and everything. Then from there we developed a song. We all had an input to it, we said about what type of music we liked, and they came up with a really good piece of music that we agreed we were all happy with.
>
> “Then once we’d got the music, we started on the words. It’s just basically discussing how we felt about it. All members were fully involved in choosing what we wanted and the words we wanted for the song. It actually worked quite quickly and went well. We talked about what we felt caring for people with dementia was about, what the illness was and how it affected our lives and all this lot, which was good. So then we came up with the lyrics to the music.
>
> “Then after that we went to an artist who did the puppet. We all decided on the puppet in the loft and created a video for it. We’re at the stage now where we’re all just waiting for it to be pieced together.”

There was no doubt that, like Rachel, Yvonne clearly saw all this as very much a collaborative process. When she said they came up with the lyrics by “just basically discussing how we felt about it,” I smiled to myself (one of the few advantages of evaluation by phone) because I knew from experience how strategic these discussions actually were.

Needless to say, Yvonne was another person who thought the song was “absolutely brilliant.”

> “I absolutely love it! We all agreed we wanted a happy song, so that’s what it is. We said we wanted it to look at the dementia from a positive angle. We didn’t want it to be too depressing. And the music sort of mixes Motown with a good melody. We’ve all been singing it – it’s brilliant.”

As a person not directly involved with caring for someone with dementia, what, I wondered, did Yvonne think about the impact of taking part in the monsters project?

> “I think we’ve all got a lot from it. It’s made us all think more closely about the dementia and how different people deal with it. The ladies who go on it absolutely love it and they all look forward to it every week.
>
> “The song’s educating people, it’s making people more aware that it’s not all negative. It is a *monster*, but it’s not necessarily a big bad monster, it’s also got a vulnerable side. This is what we went through when we talked, because dementia’s got lots of angles. It was good discussing it all, I got a lot from it.”

It sounded like she hoped their song would also help people in the wider world?

> "Oh definitely. I know it's not nice, because you're never going to get cured from it, but it's making people aware that it's not all bad. There's a side to it where it's not the end of the world, you can still have a quality of life, you don't have to give up. The song is saying that you *will* forget this and you *will* forget that, but there's still a nice story in it.
>
> "And it's great, how they can create a song out of all what we've said. It was great how we got our own input and we could say 'oh, we could maybe do it *this* way.'"

In her working role, getting the dementia message across was clearly of huge importance to Yvonne.

> "At Butterflies, we're in the position where we've got to shout loud to get the change. Things *are* improving and dementia awareness is getting out there and people *are* listening now, which is good. I'm feeling that, with the song, because it's upbeat and everything, it's something that people could just listen to. The idea is that they can listen and get something out of it, but hopefully if they go and research the story behind it and find out what it's about and get more educated about dementia, the more awareness about it there is out there, even though people are not involved, the better it's going to be for people."

Yvonne talked about the project's development and found it hard to pinpoint any particular aspect.

> "I've just enjoyed it all, from start to finish! I joke about my singing and I'm not very musical myself, so if someone says they're gonna do music or a song or something I think 'oh no, I'm rubbish!' but when *they* do it and the way they do it all and they write the song, you think 'I've been involved in this song and this song's absolutely fantastic' – it's just amazing really, what you can do.
>
> "The guy who's making the monster's made this puppet and an attic with all this stuff in miniature. It's real cute. He had a puppet that he showed us and we all liked it so much. He listened to what we said about it and tweaked it, did a few bits to it until we really liked it. So we had some input to that as well. And we had input about what goes in the loft, because we had a session about what sort of things are meaningful to us, and then he asked us to send pictures of things that meant a lot to us, so we still own it all, we're still part of it, right through. These things from our past are going in the loft, so we recognise it and say

> ‘oh yeah it’s part of us,’ which is great, because then that’s involving us at every stage.
>
> “Peter and Sally were leading us all when we were talking and then grabbing our ideas and saying what about this, what about that. We just came to a mutual decision about the attic. I can’t remember who mentioned it to begin with, but we all just went oh yeah, that’s great! So then we elaborated on it.”

There it was again – the ‘cute, mischievous’ monster – at such odds with my own perception.

Yvonne said she would definitely recommend the monsters project to other carers, but wondered about the mention of music:

> “You see, sometimes people are put off when you say it’s a musical project and they go ‘what? *I’m* not musical, *I* can’t do that sort of stuff!’ but you think ‘just try it’, because no matter what your level of talent or knowledge is, it’s just brilliant. And then once you’ve explained to people what it’s all about and they try it … Well, the ladies who’ve been in our Zoom group, they all big it up as well.”

There was definitely a common thread here – everyone I’d spoken to so far had talked about their willingness to ‘give it a go.’ Does this characteristic go hand in hand with the element of fun?

Yvonne felt that if the groups had been running as normal, more people would have given it a try and they would have had more uptake.

> “Because for the generation of people it’s aiming at, it’s technology that puts them off. Not everyone’s keen on the technology, so they’d struggle a bit to get on. But it’s like Dot. She had a bit of a struggle to start with, but now she’s on and away, and she’s there every week, because she knows what she’s doing now.”

The timing of the sessions could also pose problems:

> “It’s the nature of the illness. It can be quite hard getting the project fitted in. Especially mornings. They struggle to do the mornings because they’re too busy caring. So it’s not the actual project, it’s the practicalities around it.”

This resonated with the groups’ request to me when I joined them for the Zoom sessions – “can you ring us after half past four though please, luv? else we’re too busy.”

Like Dot and Rachel, when it came to looking at My Pockets as an organisation, Yvonne was full of praise.

> “I think they’re brilliant. They’re very professional. They’re all lovely, friendly people as well – they’re very approachable. They take in what you say and then they direct it in a direction that they want it to be.”

She particularly welcomed this direction.

> “You’re not going off on a tangent all the time. Because sometimes when you get these things you can go off and achieve nothing, you just spend the whole session just gabbing and chatting. Whereas Peter and Sally direct us back to what we’re there for and encourage us to get it down. They keep it focussed.”

When I spoke to Butterflies volunteer Madge, I instantly saw how important it all was to her: she has lived almost all her adult life as a carer. Firstly for 19 years caring for her daughter, whose severe autism left her unable to speak, and then for her husband, who had dementia. She began by explaining why she volunteered with Butterflies:

> “My husband had dementia so we went to the group together. He went to the men’s group and I went in with the ladies. Even when he passed away, I was still going in with the ladies. Then one day I thought about doing more by helping with the men, bringing them teas and coffees, because you’ve got to keep them hydrated. So I asked June if I could volunteer. I felt in some respects that helping the men was like helping my husband as if he was still here. And if you’re helping the men, you’re also helping yourself.”

Madge keeps abreast of developments by attending ongoing training offered by Butterflies and knows that “the types of dementia are different but they’ve all got similar traits, but then people react differently to it as well.” In terms of the project group, this was a double-sided coin.

> “It can be difficult sometimes, because you know what everybody’s going through but you don’t like to pre-empt it, because everybody’s different. And when you get your diagnosis, they don’t give you the prognosis – they don’t tell you how it’s going to progress.”

The monsters project was giving Madge “something else to focus on at the minute rather than this pandemic, which is helpful,” although she said she would still have taken part, regardless. I asked why this was:

> “I feel I can get across what it’s like to be a carer. It can be really quite emotional in the sessions, because it brings back memories and all the emotions and you can get quite worn out with it. But I think that’s a good thing. It’s not always a good thing to lock your memories and emotions away. It helps to talk about it.

> "I've done it back to front, if you know what I mean, from dealing with no speech to talking to ladies who've got husbands whose speech is starting to go now. My daughter's had no speech for 19 years, but she's still alive, so I've still got the caring. That's difficult in itself. So I understand where ladies are coming from when they mention the difficulties they're having with their husband's speech.
>
> "And when we were all talking about dementia and how it was our own particular monster, everyone was 'I'm not his carer. I'm his *wife*.' So we discussed all the different things that people were saying, about what we thought the monster was, and it all got written down, then the words for the song came out of that. It's all going really well, it's really good."

To hear Madge talk about carers and wives took me back to the issue of identity. It seemed the monsters project allowed the participants to peel off the label of 'carer', albeit for a short while in their busy day, and be a wife, a daughter, a mum … and to be themselves.

By now, it came as no surprise to hear that Madge was another person who had "never done anything like it before." The pattern continued:

> "I'm not musical and I can't sing, but I think it's good. I'm the sort of person who thinks 'I'll just give it a go.' James has got talent that I don't have, so you appreciate them, with James doing the music and Peter doing the words. I've not got the confidence to do anything like that [on my own]. It's a real skill."

Whilst the participants didn't fully create the song themselves, they were definitely not just observers. Without their opening up about dementia and agreeing on their monster, there would be no authentic lyrics. Without James' music, there would be no professional home for the lyrics to live in. There was undoubtedly a collaborative, two-way process at work.

Madge believed it was important that the song was upbeat.

> "You don't want it to be all doom and gloom, because it's *not* all doom and gloom – you've got your good moments and your bad moments. Those monster moments where things are just not right."

She went on to explain how the project had helped her make friends.

> "Even though I'm not there looking after their husbands, I've made friends with the ladies, which has been good, because before that I was isolated and didn't have many friends. Because usually, when dementia gets mentioned, people avoid you. I think it's partly because of people not understanding it and also because you've not got time for socialising any longer,

> because you're too busy looking after the person you're looking after."

This fitted with my initial surprise that the carers willingly engaged with looking at the darker side of their lives. Here was a project where people did the complete opposite of avoid them. It offered them a supportive, social environment to talk about what well-meaning outsiders might see as 'the elephant in the room.' An elephant that now, through what was seen as people just chatting, manifested itself in the form of a cute, mischievous monster rummaging about in a miniature attic.

I wondered whether Madge had ever thought about dementia as a monster before, or whether she had always seen it purely as the disease?

> "I'd just seen it as the disease. It all links to Butterflies and their attitude towards it. Their attitude is that it's about *living* with dementia, it's not about *dying* with dementia. But I'd had it in my mind that dementia was death. Whereas actually it's about living with a monster."

Lastly, I talked to Shirley, whose daughter June had founded Butterflies when her dad was diagnosed with dementia, "because there was absolutely nothing that couples could go to together."

Shirley found the monsters project "really enjoyable." There was yet another interpretation of the song:

> "The little song that we wrote, with James singing, it's really, really good. It's like a rumba. I can imagine some of the Strictly Come Dancing people dancing to it. I said to them all 'if Sir Tom and Michael Ball can have a number one, so can we!'"

When talking about the attic, Shirley brought a lump to my throat:

> "We haven't got any wedding photographs, because we couldn't afford any, but we were married 59 years, so we didn't do bad, did we, even with no photographs.
>
> "I just have to look across the room here and I can see the two of us at another wedding, and there's another photograph alongside it of George when he was 21, and then there's another one where he's there with our dog. So he's here all the time."

She went on to tell me about various members of her family, including her 16 great grandchildren, plus her love of painting and her experience of Slimming World … it was quite difficult to bring her back on track, other than her telling me she was "a technophobe really, but I'm OK with Zoom now."

The conversation quickly came to an end when Shirley told me it was almost time for the coronavirus press conference, “and hopefully Boris will give us a bit of better news.”

Looking back on our conversation when I came off the phone, it was not at all surprising that Shirley would have much less to say about the monsters project. It was linked to her daughter’s organisation, of which she was clearly very proud, so why would it be anything less than wonderful? I smiled and switched on the TV.

CONCLUSIONS

Social interaction

In the Zoom sessions, everyone relished the chance to talk, and this was also the case during my 1:1s. When I phoned people, I got the firm impression that all bar one were lonely and hungry for conversation. They talked about their family, vaccinations, and memories as much as they did about the monsters project itself: everything from Madge’s favourite ‘soaps’ to Dot’s sun-loving husband being nicknamed ‘the greasy chip!’ When we eventually said goodbye, the carers thanked *me*, often telling me to look after myself and hoping I got my Covid vaccination soon.

This raises questions about uptake. If the sessions had no central focus – no monster, no song, no film – and were purely advertised as ‘a chat’ about nothing in particular, in the late afternoon, they might have attracted just the same level of attendance. Possibly even more, because of the “I’m not musical” people. However, the conversation would very probably not have reached such depths about the issues around dementia and caring, and there would have been no tangible outcome they could be proud of, no creativity, no play, no message for the wider world, etc.

Either way, the participants valued the fact that here were people who were taking an interest in *them*, rather than focussing solely on the person with dementia.

Sessions by Zoom

The use of Zoom was accepted – by all concerned, including My Pockets and me – as being better than not meeting at all. Some people might have been put off because of the technology, but for others it was a chance to get to grips with something new, and everyone knew it was only a temporary measure. The timing of the sessions was not always ideal, particularly mornings, because of carers having so many other commitments.

Risk taking

Inviting people to open up about caring for a loved one with dementia was certainly risky. However, it paid off. I would attribute this to the fact that they could be themselves for a while, sharing their thoughts and feelings with other carers in an environment that actively encouraged it, with no judgement, and no expectation for them to be an uncomplaining carer who 'just got on with it.' They could say what they wanted without the risk of being made to feel guilty.

At a personal level, there was also an element of risk for me, as the conversations took me back to my own dark place. Although I still struggle to see beyond the disease to a mischievous monster, it has opened up new trains of thought, and I find myself wondering what items I would put in my parents' attic. I also find it comforting to know that people such as Madge, who had never thought of dementia as a vulnerable monster before, have come to see it in a different guise.

I am reminded too of how I instinctively saw my sister's cancer as a cackling hobgoblin running amok around her body. Did I do that to make it easier to bear? Perhaps turning dementia into a monster has allowed the carers to make more sense of the disease?

Yet, despite one person saying she thought a lot of people would benefit from taking part in the monsters project, it strikes me that it would lose efficacy if it were repeated. Much of its success seems to come from the learning aspect – both on the part of the carers and of My Pockets – which has its own energy attached, born of curiosity and freshness. Replicating the project, especially if done several times, would very probably weaken it and make it pedestrian and predictable.

Identity

The project raises all sorts of issues here. Taking the common analogy of ripples in a pond, at its centre is the person with dementia, losing their identity. Without inviting it, the person caring for them becomes labelled 'carer,' which leads them to lose some of their own identity. (In some cases, this can have serious consequences – one carer I spoke to was diagnosed with anxiety induced psychosis.) The dementia itself has an identity, which varies widely according to the form, and carers on this project take its idiosyncrasies and create a monster. Even the music that eventually ripples out has its own identity crisis – is it rumba, is it Motown, is it melodic? The one thing it does know is that it has to be upbeat, however dark its words.

The song

There is no doubt that both songs are catchy. However, some people might have been put off by the description 'a music project.' A number of those taking part said they had been a bit wary because of this. Their willingness to give things a try had got them past that wariness, but for others this might have been enough to put them off.

The participants were all very happy with the process. They had never taken part in a creative project like this before, so it was exciting for them to find their input being used as the basis for a song. They were perfectly happy for the words to be ‘tweaked’ and when it came to the final outcome they were full of wonder and awe. I found myself questioning how this could be? Wearing my creative writing hat, any ‘tweaking’ would have been very hard for me to swallow. I noted that, for the carers, the important thing was that their words had not only been heard but had been listened to.

This sense of collaboration and ownership also carried through into the attic. They thought carefully about their choice of objects and very much appreciated the fact that the scene reflected their personal experiences.

My Pockets

Everyone was genuinely surprised by the team’s creativity. They’d never imagined their group discussions could be transformed, with a bit of collaborative ‘tweaking’, into a film with a catchy song, all of which expressed their personal thoughts. What’s more, it was all created much more quickly than they had expected.

It was not hard for me to see My Pockets’ magic at work once again. Rather than deliver a firmly structured project that steered the participants towards a pre-determined outcome, they took the basic concept of monsters and just ran with it. By taking risks and experimenting, everyone learns. When the end product does arrive, it’s one that the participants take ownership of and feel proud of, and, whilst that end product is not quite there yet for this monsters project, there’s no doubt that the carers are eagerly anticipating it. They were proud to tell me of their hope to ‘show it to people’ during Carers Week in June.

The Butterflies link

Without exception, all the carers expressed huge appreciation for Butterflies and the work they do. Their comments showed me that June and her team were still working tirelessly and were as well respected as ever. In fact, the project participants are so closely linked with Butterflies that sometimes in the course of conversation with me I needed to ask them to clarify who or what they meant when they referred to “them” or “it.” I got the sense that people were more prepared to take a punt on the monsters project because of it being recommended by Butterflies – if June recommended they give it a try, then it must be good.

Their comments about Butterflies in general included:

“Before my mum went into the care home, I was really struggling trying to find carers, having lost my dad and then going head-first into caring for my mum. But June directed me towards help – the social prescribing team and everything – and without her I would have struggled a lot more and maybe wouldn’t have been able to cope.”

“We went to the Alzheimer’s group as well … but there’s a lot more people there than at Butterflies and I think it’s got too big for mum. Especially now, because she won’t have been to anything for over a year by the time we’re able to get back. I think Butterflies might be easier for her to get back into. There’s not as much noise when you’ve got a smaller group.”

“We’ve only been with Butterflies maybe going on for two years. But they’re very good. My husband likes going. They keep them entertained, give them projects to do, and it keeps the men’s brains going.”

“June’s got a course that she gives to the carers and the volunteers as well. So you can find out more about dementia itself, because there’s a lot of different types. The training’s ongoing, because every so often June will come up with something new for us to learn. It depends on funding of course, right enough.”

“People from Butterflies have been honest when they say ‘this is how it is’ when they’re talking about how it is to live with someone who’s got dementia. But you only get to see the tip of the iceberg.”

“Some ladies have been to other groups and they say that people in those are really quiet and didn’t really talk, whereas when you go to Butterflies you do talk.”

“Since I had my daughter and got isolated I’ve never had much of a life, because I was looking after her. Before she went into residential care I had some mental health problems myself, so I know how valuable projects are that are to do with mental health. But it’s about knowing how to access things. If you’re already isolated, you don’t get to hear about these things, so then you feel even more isolated. But Butterflies give you help with all that, tell you places you can go and things you can try.”

“With Butterflies, you need someone to tell you about them. The person who came to see Michael about his mental health, she was the one who put us in touch with Butterflies in the first place. So it’s through people like that.”

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