Compassionate Design - HUGs on Prescription

Professor Cathy Treadaway [0000-0001-8325-3318], Dr Jac Fennell [0000-0001-8608-1742] Dr Abdul Seckam [0000-0002-4516-9366] and Aidan Taylor [0000-0003-3040-1502]

[1,3,4] Cardiff Metropolitan University, Wales, UK
[2] University of the West of England, Bristol, UK

ctreadaway@cardiffmet.ac.uk

Abstract. There is a growing need for well-designed innovative products and services for people affected by dementia. Governments and charities are offering a range of business support to encourage the development of commercial products to address this need. This paper describes how HUG, an output from LAUGH and LAUGH EMPOWERED academic dementia research in the UK, has been successfully translated into a commercial product via accelerator start-up business funding. HUG is being used in care homes and hospitals in the UK to reduce anxiety and improve the quality of life of people living with advanced dementia.

Compassionate Design methodology has underpinned this work. Personhood, sensory stimulation, and connection with others have been used as three key principles to ensure that the design meets the needs of people living with dementia in the later stages of the disease. Loving kindness for the person living with dementia (product user) has been central to the design process and involvement of people affected by dementia at various stages of the disease has been crucial to the success of the product.

The studies described in this paper provide an example of how an output from academic research has been successfully translated into a commercial product that is now improving the lives of people living with dementia.

Keywords: HUG, Dementia, Product, Design Research.

1 Context

There is a global need for better designed products and services that help people live well with dementia and maintain their quality of life [1].[1] A growing number of academic research projects focus on understanding how to design appropriately for people

[1] https://www.ukri.org/opportunity/healthy-ageing-challenge-designed-for-ageing/

living with dementia [2].[2] There is also increased interest in this expanding market sector from the manufacturing and design industries, who seek guidance from academia and the care sector on how to create better products and services. Governments are encouraging researchers and industry to work together to address this global need with catalyst, seed, and accelerator type funding.[3] These schemes bring together design experts with industry to translate good ideas into commercial products. Nevertheless, very few design concepts emerging from academic research, ultimately make it to market at an affordable price and are successfully integrated into dementia care.

This paper focuses on one success story. It describes how an output from academic research in the UK has been translated into a commercial product that is improving the quality of life of people living with dementia [3-4]. HUG is a soft therapeutic comforter that was originally created for people living with advanced dementia. The product is designed to be cuddled and has a plush textile outer body with weighted arms and legs (Fig.1). Its soft inner cushion contains a programmable electronics module, which provides the pulsing sensation of a beating heart and can play a person's personalised playlist of music.4 It is being used in the UK by individuals living with dementia in the community, in residential care and NHS hospitals, where it is now being prescribed for patients within individual care plans. The underpinning research for HUG began in 2015 supported by two government grants: LAUGH5 and LAUGH EMPOWERED6 and was completed in 2021.

[2] MinD; CertificationD: DesHCA; LAUGH etc.

[3] Alzheimer's Society Accelerator Funding; Innovate UK Healthy Ageing Catalysts, Design Age Institute Pathfinder Awards etc.

[4] www.hug.world

[5] Arts and Humanities Research Council grant Ref: AH/M005607/1.

[6] Welsh Government SMARTExpertise European Regional Development Funding Ref: 2018/COL/012/80839

Fig. 1. HUG by LAUGH®

The LAUGH[7] project (2015-18) sought to investigate the broad principles required to design hand-held playful devices for people living with advanced dementia to support their wellbeing. The design process was underpinned by Compassionate Design methodology, which was developed and tested through the research [5]. This approach places lovingkindness for the individual living with dementia at the heart of the process and focuses design thinking on sensory, personalised and connecting properties of the product. A collection of prototype playful objects was designed and tested through the LAUGH study. HUG was one of six outputs from the research along with the Compassionate Design methodology that guided the creative process (Fig. 2) [6].

Fig. 2. Prototype HUG from LAUGH research

Findings from the evaluation phase of the research evidenced a significant improvement in the physical and psychological health and wellbeing of the person for whom the original HUG was designed [7]. Consequently, further government funding was awarded in 2018 for LAUGH EMPOWERED, a much larger study, undertaken in both residential care and hospital contexts over the next three years. This study corroborated findings from the initial LAUGH evaluation study and led to the establishment of a university spin out company, HUG by LAUGH®.[7] HUG had been found to make a significant positive impact on the lives of people living with dementia and so it seemed imperative to make the product commercially available [4].

[7] www,hug.world

1.1 Involvement of people living with dementia

People living with and families affected by dementia were included through all phases of the research. Their contribution informed each stage of the design research from initial guidelines, concept development through to packaging and promotion of the manufactured product. The LAUGH project benefitted initially from advice from people living with early-stage dementia through the members of an Alzheimer's Society Service Users Reporting Panel. Twelve people living with advanced dementia and their families also helped to inspire the design concepts for the products that were developed. Portraits of the individuals, containing brief life history information and individual preferences, were developed to ensure the bespoke nature of the design concepts. Six of these individuals living with advanced dementia were involved in evaluating the prototype products that were developed. 40 people living with dementia and cognitive impairment participated in the LAUGH EMPOWERED evaluation study including one who was a member of the project Advisory Group.

In the final stages of the research, the HUG by LAUGH Ltd. business was established with support from Alzheimer's Society UK. Product development was guided with the help of their Innovation Team and Dementia Voices focus groups. These included people living with dementia and their carers, and provided invaluable guidance on the product offering prior to launch, including packaging and product information. Finally, a Dementia Voices group evaluated the launched product as part of a media campaign for Alzheimer's Society. At each stage in the product journey, experiences and insights of people living with dementia helped to inform the design decisions, ensuring the final manufactured product met the needs of people living with the disease. Testimonials from people who have found HUG beneficial are included on the HUG by LAUGH website (www.hug.world).

Fig. 3. Alzheimer's Society Dementia Voices focus group with HUG

(Photo: Alzheimer's Society UK)

The participation of people affected by dementia was invaluable, providing unique insights as the product developed (Table 1.). For some of those participants living with advanced dementia who were involved in evaluating HUG, engagement in the research was life changing and this was documented via a film broadcast on BBC TV.[8] Staff working in the hospital and care homes reported how being involved and having access to the prototype objects, had brought benefits not only to those they cared for, but also for themselves via increased job satisfaction [7].

Table 1. Involvement of people living with dementia

Research Stage	People Living with Dementia Involved	Numbers
LAUGH research		
Initial research	Alzheimer's Society Service Users Reporting panel Cardiff	6
Design inspiration	People living in residential care	8
Design evaluation	1 person per bespoke prototype product	6
LAUGH EMPOWERED		
Sunrise study	Residents in care home	20
NHS Hospital study	Patients in hospital	20
Product design	Dementia Voices focus group (national)	6
Packaging design	Dementia Voices focus group (national)	6
Product evaluation	Dementia Voices (Newport)	6

2 Methodology

Involvement of experts by experience, carers and health professionals has been key to the success of HUG and the underpinning research. Finding ways to capture and exploit their insights has been vital, to inform product development and the design for dementia process. The LAUGH research project used qualitative interpretivist methodologies in which data was collected through collaborative and creative methods in participatory and co-design workshops, semi structured interviews, and focus groups. Storytelling, observation, creative, practical, and playful activities were used to stimulate discussion and generate knowledge about dementia to underpin the later design phases. Video and audio recording of these activities was used to capture participant responses. Data was analysed thematically [8], through a mix of deductive and inductive approaches and in

[8] https://www.bbc.co.uk/news/uk-wales-50237366

response to existing literature concerning dementia, design, and wellbeing. Compassionate Design principles (Fig. 4). guided the creative process to ensure each design was stimulating to the senses (to keep the person in the moment), highly personalised (to maintain their dignity and retain self-identity) and able to connect (the person to others and the world around them).

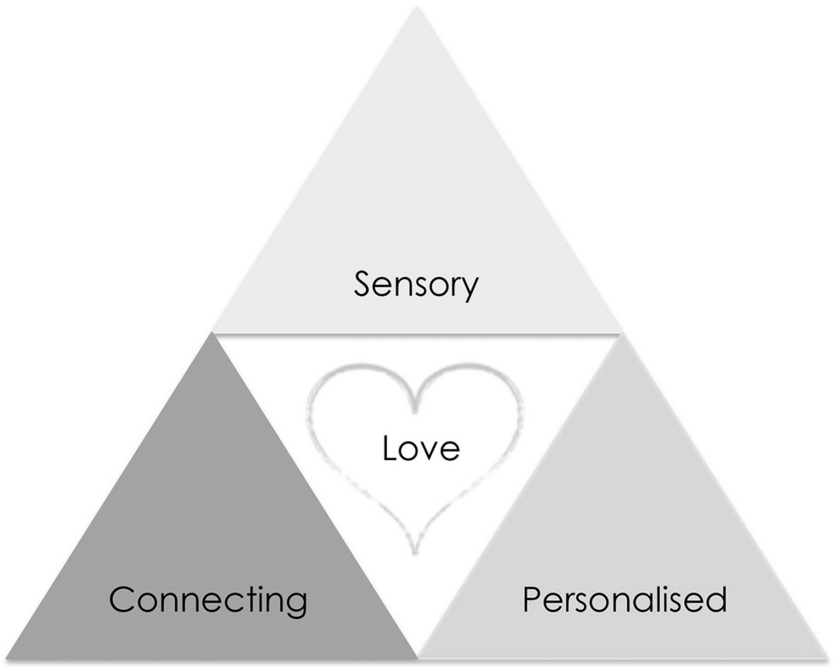

Fig. 4. Compassionate Design

Participants living with advanced dementia were selected for the research in collaboration with the care home managers who knew the people and their families well. The criteria for selection included a diagnosis of dementia (in the advanced stages) with a family member or caregiver who knew the person well enough to interpret their emotional responses via non-verbal cues such as facial expressions and body language. These carers were involved in the product evaluation with the person living with dementia. 8 individuals living with advanced dementia participated in the design phase of the LAUGH research.

The LAUGH EMPOWERED research (2018-21) involved two evaluation studies: one in a residential care home and the other in a hospital context. Both studies involved 20 participants receiving a HUG. The evaluation tools included the Pool Activity Level

Instrument (PAL) [9] and an Adapted Bradford Dementia Wellbeing profile.9 Staff in the residential care home and hospital were trained in the evaluation methods prior to the start of the research, with the intention that it would be possible to compare the data at the end of the study. Unfortunately, the hospital study coincided with the Covid pandemic10, and it was not possible for medical staff to complete the planned outcome measures for the study due to extreme work pressures, or for researchers to enter the hospital. A pragmatic approach was taken to collect data and to ensure that the study did not fail. A series of online qualitative interviews were undertaken with hospital staff, towards the end of the pandemic when the situation had eased significantly. These comprised a series of 5 focus groups with up to four practitioners representing the interdisciplinary medical teams (n=20 participants).

University ethics approval was gained for both LAUGH and LAUGH EMPOWERED studies. IRAS11 ethics approval was achieved for the NHS hospital study and an ongoing 'process method' of consent used for research participants living with dementia [10].

3 LAUGH EMPOWERED

LAUGH EMPOWERED was funded by Welsh government over three years from 2018 -2021. The aim of the project was to undertake a larger evaluation of HUG in both residential care and hospital contexts. The project partners were Sunrise Senior Living Ltd and NHS Cardiff and Vale University Health Board (Llandough Hospital). The first task for the research team was to batch prototype 40 HUGs to ensure sufficient identical products were available for evaluation in both contexts [11]. NHS staff contributed to revisions to the design of HUG to ensure that it complied with NHS infection control and safety regulations. The soft textile outer shell and the internal electronic unit were each made by hand, as it was too expensive to manufacture such a relatively small quantity.

3.1 Findings from the LAUGH EMPOWERED care home study

While the HUGs were being made, ethics approval was sought, and staff trained in the use of the Pool Activity Level (PAL) instrument and the Bradford Dementia Well-being profile (BDW). Participants were selected by the care home management and consent gained from families for participant inclusion in the study. Baseline assessments were made of participants' cognitive and functional ability (PAL) and wellbeing (BDW)

[9] https://www.bradford.ac.uk/repos/health/Bradford-Well-Being-Profile-with-cover-(3).pdf
[10] March 2020
[11] Integrated Research Application System (IRAS) – UK National Health Service (NHS)

prior to being given a HUG. They were assessed again at 3 months and 6 months into the study. In any dementia study, attrition is inevitable since it is a terminal disease. In the Sunrise study, data was collected at 3, and 6 months for 16 out of the 20 participants. 87% of those participants who had used a HUG for 6 months showed an increase in their wellbeing. Of those, over half the group showed an increase in their functional and cognitive ability as measured by the PAL Instrument. These findings are particularly significant as dementia is generally associated with neurodegenerative decline [4].

Those participants who received a HUG in the study were allowed to keep them. There were many heartwarming stories from family members and care staff indicating ways in which participants had enjoyed their HUGs and formed attachments with them. A BBC film made about this study can be viewed online12 and includes positive accounts from family members about the benefits of the product experienced by people living with dementia. Media interest in the study led to many enquiries from the public wanting to purchase the product. The university responded to this by supporting the research design team to develop a business plan for a spinout business, and to explore manufacturing and selling the product (Fig.5).

[12] https://www.bbc.co.uk/news/uk-wales-50237366

Fig. 5. HUG being used by a person living with dementia

3.2 HUG on Prescription

At the same time as the care home evaluation was underway, the NHS IRAS ethics process was initiated, and hospital staff were trained to use the PAL and BDWP tools. Half of the HUGs were distributed to patients on the inpatient dementia wards (n=10) and the rest to selected patients in the Stroke Rehabilitation unit (n=10). The selection criteria included a diagnosis of cognitive impairment following stroke or dementia and presentation of symptoms of anxiety and agitation. Patients were prescribed HUG with an associated care plan once ethical approval had been gained and consent forms signed by participants and families.

There was some initial delay to the start of the evaluation due to reporting requirements from the funder and lack of NHS staff time to implement the study. This was followed in March 2020 by the beginning of the pandemic when reporting for all research was put on hold by the NHS Health Board. Nevertheless, patients continued to be prescribed HUG and although the evaluation tools had to be abandoned, those staff who worked with patients who had been prescribed HUG during the six-month period, were invited to participate in (post-study) multidisciplinary team focus group feedback interviews (n=20). These took place in April 2021, once restrictions on research data collection were eased and IRAS ethic approval had been obtained from NHS.

The focus group participants represented the different specialisms in the multidisciplinary medical teams who had cared for patients with HUGs. These included: doctors, nurses, psychologists, occupational therapists, speech and language therapists and technicians. The delay between the end of the evaluation and the interview data collection meant that some participants found it difficult to remember details clearly. Nevertheless, collectively they were able to describe ways in which HUG had benefitted patients and helped in their care, as well as making insightful observations, and suggestions about how the product might be improved and implemented in care.

3.3 Findings from LAUGH EMPOWERED hospital study

Patients who have been admitted to hospital are inevitably in crisis and experiencing anxiety and agitation. For someone living with dementia hospital admission may exacerbate their underlying anxiety and cause distressing behaviour. For a patient who has had a stroke, the sudden onset of cognitive impairment may be shocking and very frightening [12]. There is reluctance by doctors to prescribe anti-anxiety medication for these patients in the hours after a stroke, due to side effects. Alternative nonpharmacological solutions are particularly attractive option to try to help keep patients calm and reduce their stress. HUG was prescribed for a small number of patients who were recovering post stroke, and a group of inpatients on the dementia wards (n=20 total).

Analysis of the data collected from the NHS Staff qualitative interviews provides a rich picture, detailing the complexities of introducing a therapeutic playful object into an NHS context with critically ill patients. The interview data provides consensus that HUG was beneficial for some patients, but not all. Some patients rejected HUG immediately and it was recognised that not everyone enjoys receiving a hug or social touch, particularly if they have had difficult life circumstances in which they experienced abuse. When accepted, however, HUG provided a significant positive experience for the patient and those staff involved in their care. The ways in which the product was introduced to the patient, staff personal attitudes towards HUG and time available for practitioners to integrate it into day-to-day care seems to have impacted significantly on how each patient responded.

Findings from the study identified the following positive benefits of HUG on patients in the hospital context:

1. Providing comfort, reducing anxiety, agitation and giving reassurance
2. Improving communication and initiating conversations with staff
3. Providing company and a sense of purpose
4. Increasing oral intake: improving eating and drinking and taking prescribed medication
5. Providing an alternative to medication for anxiety (and lowering the risk of falls)
6. Enabling medical procedures and personal care to take place
7. Modifying distressing behaviours (tapping, shouting, crying)

When patients are hospitalised, they are often frightened, agitated, and disorientated due to the health crisis for which they have been admitted; they have left the safety of home and enter an alien environment, full of unfamiliar people and sensory experiences. For someone with cognitive impairment, sensory loss, dementia, or delirium, this can be devastating. Finding ways to calm patients, so that medical procedures can take place, is vital for positive health outcomes and crucial for their care and wellbeing. One doctor commented:

I think the situations where people are really withdrawn or they're showing signs of distress and you can't really sort of orientate them, I think it's really useful to be able to give them something to be able to, well, help give them a bit of reassurance and calm them down really, to enable them to engage a little bit more.

HUG was used to help reduce distress, with many of the interviewees referring to having observed the positive way in which HUG was able to help patients in their care. A doctor gave an example of one patient in particular who benefitted:

She was an elderly lady with a dementia diagnosis who was in a lot of distress…… And so, she was sort of seen as an ideal candidate for somebody to trial with the HUG. From what I remember, it was quite a marked change actually. So, when she did have it, she was pretty inseparable from it to be honest. It did settle her quite a bit and then when people did approach her, say nurses or any other therapist, or the doctors, we'd get a much better response from her.

Patient anxiety, confusion and fear can make communication with medical staff difficult, and this can impact on the quality and timeliness of care that can be provided. People with cognitive impairment or living with dementia can often be very withdrawn and staff can find initiating conversations difficult. HUG was found useful as an ice-breaker with patients and as a conversation starter. A doctor commented on how HUG had helped in communication with one patient saying: *'it was easier for her to communicate when she wasn't quite so wound up and banging things and shouting'.*

Anxiety distress, agitation and boredom can accompany hospitalisation for a patient with cognitive impairment or dementia. Wards are busy environments and there is little time for staff to stop and chat with patients when they are lonely, bored, or lacking self-confidence. HUG was described as: *sort of something to cling to, a bit of comfort, so [they] gained a bit more confidence on the ward and were a bit more orientated.*

One doctor described a patient for whom HUG became a companion:

A companion yeah! She was just much more settled if she had the HUG with her. and to be honest…. we don't have the staffing level to be persistently with somebody like that, constantly.

When a patient is agitated or distressed, they will often decline food, drink, and to take their medication. Various members of the MDT described how patients who had previously refused oral intake were much more inclined to be compliant while they were holding HUG. A physiotherapist described the *'real positives'* of using HUG around the *'feeding and the nutritional side of things'* and remembered *'one particular patient being very difficult and had a very, very poor intake, but actually after we give HUG to her she became more engaged with everything around the ward, and even though we didn't gain anything from a rehab stand point, from a purely physical side, we gained from her being able to have a bit more intake.'*

Encouraging patients living with cognitive impairment or agitation to take medication can prove to be difficult, however HUG was found to help with this aspect of care. An occupational therapist recollected:

'I can remember the HUG with the patients with dementia taking their medication as well. I think it was helping to soothe, calm them down and they were able to take their medication, whereas normally they would decline to take it.'

For patients who have delirium, dementia, or post stroke cognitive impairment there are few drugs available without side effects that negatively impact on the conditions being treated, or their quality of life. Medication can make people drowsy and more likely to have a fall, leading to further pain and distress. One nurse commented that a positive thing about HUG *'is it reduces the risk of falls, reduces the risk for medication, lessens the anxiety levels - they've gone down for the patient, and the staff around them going back and forth. So, that was hugely beneficial for the ward and for the patient.'*

Routine procedures can be traumatic for patients who are frightened, agitated, or stressed. Nursing staff commented on how HUG had helped them to administer personal care. This is inevitably difficult and takes more time when a patient is distressed. HUG was also found to help relieve a patient's anxiety sufficiently so that staff could undertake basic medical procedures:

'There was a lady, you know…she'd get quite agitated when she needed her blood pressure taken, and the nursing staff reported the doll would calm her, to allow them to take the blood pressure.'

Health professionals described ways in which HUG calmed patients down and 'took away some of the frustration' they were experiencing. The impact of a distressed and anxious patient on others on a hospital ward can be very difficult for staff to manage. Finding ways to help a patient calm down or modify their behaviour can reduce stress levels for all. HUG was found to calm and distract patients for the benefit of everybody on the ward. A physiotherapist technician presented an example of this:

'There's another lady we have who taps on furniture, arm of a chair or table and obviously for everybody in the room, you know it can be quite distracting quite annoying, I think maybe for some of the other patients. So, they give her the doll, and she would tap on the doll instead.'

Patients who have had a stroke may lose sensations and awareness of their body within space. These patients can become very anxious due to the sensation of falling they experience, even when they are laid flat in bed. The weighted limbs of HUG and the cuddling sensation that it provides can be very comforting and help give the perception of being 'grounded'. A doctor reflected on this as follows:

'We have a certain group of patients who will only be able to lie flat on their back and even when they are doing that, they still don't feel safe in the bed because of the way the stroke has affected them. They always feel like they're falling, or they are about to fall. So, giving someone some grounding, some weight down through them, can be very beneficial from a physical point of view. I wonder if that is an element of it, that weighted feature and the more sort of sensory stimulus it gives you by hugging it, that is actually a feature that really settled people.'

Although not every patient who received a HUG accepted it, the device did have a significant positive impact on the quality of life and care of those who did. It is clear from the interviews with NHS staff that, although HUG may not be the right solution for every patient, it is a useful alternative to prescribed medication to be considered for someone who is anxious and distressed. Doctors interviewed for the study observed HUG to be a useful, low-risk intervention, without the negative side effects that often accompany many of the drugs currently used. Where HUG was helpful, the improvement in the patients' quality of life was significant. For some, this was in the short-term, providing comfort in times of severe illness but, for other patients, HUG became a comforter and companion object that remained useful for the duration of their hospital stay and beyond. Where HUGs were not accepted, a variety of factors are implicated from the interview data, including patient inhibition or dislike of tactile intimacy (hugs

and body contact), personal preference (aesthetic appearance), social pressure (fear of infantilisation) and the way the device was introduced by staff to patients. Prior research has found that people living with cognitive impairment and dementia respond to the world at pre-reflexive emotional level and, even when communication is impaired, will read body language and affective responses of others [13, 9]. For this reason, the manner in which HUG is introduced to a patient will influence its therapeutic benefit. When staff lacked conviction in the efficacy of HUG as a wellbeing intervention, disliked it themselves, or felt it to be infantalising, there was an impact on the way it was introduced and then received by the patient.

4 Commercialisation

The LAUGH EMPOWERED evaluation studies corroborated findings from the initial LAUGH evaluation. They found that HUG can be used successfully to help reduce anxiety, agitation, provide a sense of purposefulness, companionship and stimulate communication. A clear argument was presented that the product would be useful and could fill a gap in the market. The LAUGH EMPOWERED project included a scoping study for commercialisation of the product and, during 2019, a business plan was written, and the pre-manufacturing compliance testing carried out. This included CE and UKCA marking13, to ensure customer safety and product liability. Funding support from the university and external sources was explored. This included an application to Alzheimer's Society for Accelerator Funding14 and a crowdfunding campaign15. Both yielded positive results. Despite the difficulties of working through the first year of the pandemic, the HUG by LAUGH Ltd. business was registered in 2020 and supported by Alzheimer's Society UK during its first year of trading. The crowdfunding campaign helped to raise public awareness of the product and resulted in two UK awards from Tech4Good16 and the first sales of the product in the UK.

Alzheimer's Society Accelerator funding provided the business with advice and financial support to manufacture a first batch of the product through 2021. The Alzheimer's Society Dementia Voices group, which includes people living with dementia and caregivers, provided advice and feedback on the product and its packaging. They also played an important role in providing encouragement and help disseminating information about the product. The Alzheimer's Society Accelerator funding was crucial in helping translate the research output into a viable commercial product and underpinning the product with user confidence. Labels attached to the product and its packaging display the Alzheimer's Society UK logo and a percentage of the profit of each product sold, helps raise funding for the charity.

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[13] CE (European Conformity) and UKCA (United Kingdom Conformity Assessment)
[14] https://www.alzheimers.org.uk/research/our-research/accelerator-programme
[15] https://www.crowdfunder.co.uk/p/hug-by-laugh-1
[16] https://www.tech4goodawards.com/finalist/hug/

Throughout its development, HUG had benefited from press and media interest, including regional and national television coverage, local and national newspaper stories, web posts and invited blogs. The affiliation with Alzheimer's Society and the university has helped the business to market the product widely, and HUG by LAUGH is now receiving interest from customers globally.

5 Discussion

Academic research frequently generates innovative ideas that can be life changing, however there is a huge gulf between a good design concept and a manufactured product. Academic researchers must learn a raft of new skills which may be beyond their expertise. The gap in knowledge involves, amongst other things, manufacturing processes, compliance, intellectual property legislation, business models and planning, marketing, and investment funding. It requires a tenacious and passionate academic research team to navigate these new territories. Start-up funding and business support can ensure that good ideas, founded in and tested through academic research, can make a positive difference to the lives of people living with dementia. HUG is now commercially available in the UK and is soon to be available to buy globally. Product users are not only people living with dementia but include adults and children living with diverse disabilities and medical conditions, as well as those receiving palliative and end of life care.

The global pandemic has highlighted ways in which social exclusion results in anxiety and loneliness, and how important affective caring touch is to individual wellbeing. In the research described, HUG was made available during the pandemic to hospital patients 'on prescription' with an associated care package. The evaluation process was inevitably severely disrupted, and the research protocol had to be adapted to ensure that qualitative data from healthcare professionals was gathered post-trial. Continuity of the study throughout the lockdown period ensured patients were able to receive the therapeutic benefits of using the product during a period when there were stringent restrictions on visitors, and individual anxiety levels were particularly high. Acceptance of a product like HUG poses difficulties for health sectors who usually require hard quantitative evidence to prove efficacy[17]. Nevertheless, the pandemic has revealed ways that new psychosocial approaches, outside usual the medical model, can provide successful person-centered solutions that can improve quality of life for people affected by dementia and other disabilities.

[17] Further hospital studies are currently underway in the UK that will mitigate the limitations of the one reported in this paper.

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