







The impact of forced innovation during COVID-19 on Fatigue and Breathlessness (FAB) follow-on sessions 26th February 2021

> Alison Christian Physiotherapist Hospice Isle of Man







#### FAB

- 8 week structured rolling programme
- COPD, cancer
- Physical activity, education, relaxation
- Staff-led
- Invited to attend FAB Follow-on on completion

#### **FAB Follow-on**

- Weekly
- Drop in
- 1-hour long
- Self-led exercise session in gym
- Unstructured session
- Supervision from staff
- Caseload of 19

#### Zoom FAB Follow-on

- Weekly
- Drop in
- 1-hour long
- Staff-led
- Structured session
- Supervision
- 1:1 Telephone support



23%

3

77%

10

# **Patient characteristics**

Respiratory conditions (e.g. COPD)

Cancer 1 Neurodegene (e.g. MND, MS

Neurodegenerative conditions(e.g. MND, MS)

Other: Old age, rheumatoid arthritis, scleroderma and polymyositis





# Zoom sessions compared to Hospice-based sessions

86% Thought that the Zoom sessions were 'good' (12 out of 14)





Felt that Zoom sessions were 'no different' or 'better' than sessions held at Hospice (9 out of 14)

# During the COVID-19 outbreak...

71%

Felt that Zoom sessions were 'helpful' for social contact (10 out of 14) "Yes it has been great to see the staff and the other patients who have participated and we have all had a quick chat at the start and end of the sessions. It has been great to still have the sessions albeit delivered in a different way"

"As I was shielding at home the Zoom sessions were one, regular, contact with people outside"

"It was nice catching up with the group"

"Just nice to see different faces and hear different voices"



# 64%

### Felt that Zoom sessions were 'helpful' for psychological support (9 out of 14)

"Having this contact each week had been helpful"



"It helps me to see and know that the world goes on"

"I did look forward to the sessions"

# During the COVID-19 outbreak...

77% Felt that the individual telephone support calls were 'helpful' (10 out of 13) "... is always so cheerful and helpful and ready to give advice if needed"

"Definitely, as I can talk on a one to one basis"



"I have been given help. My husband is not well and it helps to know someone cares"

"It is lovely that the contact has continued in this way and presents an opportunity to discuss matters that wouldn't be appropriate to discuss amongst a wider group"

"Comforting to have a contact if needed"



# **Advantages of Zoom**

"Company during isolation"

"Not missing out on exercise" "Keeping in touch, and a constant reminder of dealing with breathlessness"

"Working at own speed and not having to ask my husband to take me"

"No travelling to the Hospice. I find it exhausting getting ready to go out"

"Easy to access using zoom and the directed exercise sessions have been very good. We probably do more exercise via zoom than we would at Hospice, where we would spend time chatting amongst ourselves too"



# **Disadvantages of Zoom**

"Not being able to use exercise equipment"

"You can't beat seeing people in person" "I find it difficult to handle the zoom principle"

"... Not having the garden walks in the good weather"

"Not really having contact with people. I miss the chats with the people who attend"

"None really other than the fact broadband or computers seem to lock up rather frequently leaving us with a frozen picture whilst the image is frozen"



## **New activities**

**77%** Said they wanted to continue doing exercise to music in sessions (10 out of 13)

53

"I've enjoyed the music, especially Queen in TT week. More please"

"Makes it more cheerful – and challenging, trying to follow"

"Very relaxing"

"Really beneficial"



92%

Said they wanted sessions to continue finishing with a short relaxation (12 out of 13)



# Reminders about breathing tips





# Going forward: What would suit you best?





## Attendances





# **The Challenges**

#### Initial

Getting patients on board Technology issues – staff and patients Communication Resources

Equipment



Emathing techniques and constitues are invaluable in helping yoo to manage your breathingment.

Healthcare Profe

Job Vacancies

A useful tool to help with your broathing economics.



COVID-19

About Us

e-Newsletter

**Contact Us** 

Events

Online Giftshop

Helping you improve and manage your strength and tradaction.

### Discovered

Patient safety and risk assessment/communication

The "silent audience"

Adapting content for differing levels of ability

Varying the content

Increased stress level!



A balanced diet and the right nutrition can help with your rehabilitation.



Physical activity can help improve your functional canabilities.



How best to plan, prioritise, pace and simplify your daily activity



Sleep can help you to rest, relax and 'recharge'. It enables us to cope better with physical activity and



Deing rested and taking some time to practice mindfulness and relaxation can help your wellbeing.



Our Rehabilitation Team bring to you some useful exercise videos you can do from home.















### Fatigue and Breathlessness (FAB) Follow-on Session



### **By Alison Christian**



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Stay in touch, sign up to our newsletter at www.hospice.org.im



IFIC Presentation Feb. 26, 2021

Bruce Elliott, CEO www.MemoryLaneGames.com

Digital health **apps** to improve lives of Dementia patients and carers. **"The app store, not the drug store**, is the future of scaleable healthcare, so critically needed in dementia care in these challenging Covid times."

Bruce Elliott, CEO



### Why we do, what we do:

50 Million Dementia

Patients Worldwide

## 150 million

Patients x 3: adding just 1 family member and 1 carer or healthcare worker



Digital health is the answer Prescription apps are available today for diabetes, insomnia, mental health, IBS, etc. <u>But not for dementia.</u>

# Memory Lane Games

# Digital health apps specifically designed with dementia patients.

#### Localised reminiscence therapy

- starting in the Philippines, Uganda and India. FOR FREE.

#### **ORCHA-certified "Digital Health App - Condition Management"**

- GDPR-compliant; available in 102 NHS Trust micro-app stores

#### **Social prescriptions**

- In 2022, we aim to qualify as a prescription app in Germany
- under the new German Digital Health DiGA regulations.

Engaging, evidence-based dementia therapy apps, accessible for all.

Our free app comes with **hundreds** of fun, easy-toplay games, selected just for you. Enjoy!

Cognitively-stimulating

Conversationstarting

Trigger positive memories





Change and the second second

### **Frustration-free design**

Benefits for patients <u>and</u> carers Localised for reminiscence therapy



Our **"search bar"** helps carers and healthcare professionals <u>easily customise</u> the experience to increase user engagement

#### Search most UK cities / towns (120 games live)

## Search popular hobbies/interests

(woodworking tools to garden birds, etc)

Search 1950s music, classic cars, puppies, babies ... more games every week



### Or even search for games by language

(we work with national Alzheimer's Associations to localise by region)

Search Tagalog (Philippines) Search Hindi Search Luganda (Uganda) Search German more to come!





### The Alzheimer's Disease Association of the Philippines (ADAP) has assigned a 10-person working group to build games for our app:

- Dementia specialist neurologist; Memory Cafe nurses;
- Clinical researcher; Psychologist, volunteer families and carers
- They have also offered to replicate our Observational Study in The Philippines
- All at no cost to Memory Lane Games



### What our partners are saying

"Memory Lane Games is cognitive rehab at home, ideal for patients unable to come into our clinics due to Covid."

> Dementia-specialist neurologist, ADAP Alzheimer's Disease Association

#### **The Philippines**

### What our partners are saying

"Memory Lane Games is not about playing games; this is about managing the condition of our dementia patients."

> MD, Executive Director, Uganda Alzheimer's Association.

#### Uganda

### What our partners are saying

"I use Memory Lane Games <u>as a reward at the end of my</u> <u>speech therapy sessions</u> with my eldeerly clients. Everyone loves playing these fun, accessible games.

Registered Speech Therapist **Boston MA** 

"I use Memory Lane Games with my patients and I am <u>able to get</u> <u>much more done</u> while they are happily playing!"

> NHS Nurse, England.

#### US, UK ...

# How we help:

#### **Patients:**

- fun reminiscence activity
- easy to play
- addresses social isolation and social interaction

#### Carers:

- Precious 12 minute "break"
- Positive, quality time

#### Family:

- Conversation-starters
- Participate in care





### "I know that one!"

### Personalisation: families can add their own images





# **Personalisation:** Creating your own games - it's very easy ...



# **Personalisation:** *"Mum played 6 games today and liked 4!"*

Families can opt-in to receive notifications by securely connecting their apps, with consent.



# Personalisation: sharing of voice memories



You may hear memories from loved ones you've never heard before!

### **Personalised dementia therapy - patient centric**



### **Our hypothesis:**

Personalised dementia therapy can improve the <u>quality of life</u> for dementia patients and carers.

# Our Observational Study - Ethics approval: March 2021



### Scholl Academic Centre (Hospice IOM)

- 30 pairs of dementia patients and carers
- Randomised controlled study

### **Primary outcome:**

The quality of life of people with dementia and their carers based on DEMOL/C-DEMQOL scores compared to people using the non-personalised game.

#### Secondary outcomes

communication, mood and cognitive function

### **Seeking Prescription app status - Germany**

#### Oct 2020: German DiGA regulations Key requirements for Fast Track:

- Patient safety
- Identified population
- CE Medical Device certification (app)
- Observational Study published

NOTE: "medical benefit" does <u>not</u> need to be clearly established in initial study to enter fast track; indicative results accepted which can then be demonstrated in 12-24 months following acceptance We're on track to meet DiGA requirements for 2022:

#### In progress:

- **CE Medical Device certification** (Class 1 - lowest level of certification which qualifies under DiGA)
  - Our randomised controlled Observational Study, has been designed to meet DiGA requirements and is also based on a 2017 US FDA approved clinical trial on an app for dementia patients with tablets and generic images.

### Clinical pipeline: 2021-2022

### 2021

Observational Study pending approval

- Improving quality of life
  - Improving quality of life of patients & carers
- Target completion Q4 2021

### 2022

Al-optimised gameplay by cognition levels

### R & D (our longshots) 2022-2025

- Identify leading indicators for health outcomes in dementia patients with AI machine learning:
  - potentially identify increased fall risks (high cost in elderly care).
- Explore "cognitive maintenance" benefit from longitudinal gameplay driven outcomes

Our IP = AI + clinical evidence + large opt-in user data sets

### "We started out building games for our Mums.

Our Co-founders' Mums are 91 (dementia) and 86 (sharp as a tack). From their shared love of old families photos, we began with an idea to turn memories into games. Our simple idea is catching on, around the world.

#### Download our free app today:

Apple App Store Google Play Kindle

### www.MemoryLaneGames.com

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Thank you

