Reaching the younger community online: Dementia Outreach, Awareness and Supporting Young Caregivers

Melissa Chan
PROJECT WE FORGOT (PWF)
ABOUT PROJECT WE FORGOT (PWF)

A movement to advocate and **encourage awareness of dementia among the young** and a **community to inform, empower and support younger caregivers** (ages 39 and below) to persons with dementia.

WHY YOUNG CAREGIVERS?

Young caregivers are often left to deal with the **stigma that the illness carries**.

They **feel isolated** because their peers do not understand what they are going through.

They **carry the guilt when they have to choose** between growing up and find their ‘self’ vs. having to shoulder the responsibilities of caring for their loved one.

They are usually **just starting their own lives, juggling work, school and social lives**, when they are faced with the task of having to take care for a loved one with dementia - parent or grandparent.
AN OVERVIEW: THE 4 PILLARS OF PROJECT WE FORGOT (PWF)

**ALZSocial**
- Online chat community for younger caregivers to connect

**Humanising the journey through story-telling**

**Online community**

**Global collaborations & partnerships**
- Working with a global network to gather insights and design workshops & programmes
- Survey & research work

**Offline local chapter activations**
- Singapore:
  1. Outreach Events
  2. Support Activities

**Supporting local chapters kick-off:**
- (Malaysia, Israel)

**Workshops, programmes & training**
- Toolkit to support young caregivers within Schools & Organisations
- Training web-app to educate:
  1. Youth & Teachers
  2. Young Adults
  3. Corporates

**Project We Forgot**

**ALZSocial**
- Online chat community for younger caregivers to connect

**Humanising the journey through story-telling**

**Online community**

**Global collaborations & partnerships**
- Working with a global network to gather insights and design workshops & programmes
- Survey & research work

**Offline local chapter activations**
- Singapore:
  1. Outreach Events
  2. Support Activities

**Supporting local chapters kick-off:**
- (Malaysia, Israel)

**Workshops, programmes & training**
- Toolkit to support young caregivers within Schools & Organisations
- Training web-app to educate:
  1. Youth & Teachers
  2. Young Adults
  3. Corporates

**Project We Forgot**

#PWFALZ

@PROJECTWEFORGOT
OUTCOMES WE AIM TO ACHIEVE IN 3 YEARS

Increase availability of formal and non-formal support for young caregivers

Increase awareness and education amongst young people on the impact of dementia on both caregivers and persons with dementia

Increase awareness of needs of caregivers at formal institutions (schools and workplaces)
**PROJECT WE FORGOT (PWF) / THE ONLINE COMMUNITY**

**Online chat community for younger caregivers to connect**

**Humanising the journey through story-telling**

**YOUR AID**  
A Global Collection of Articles for Caregivers & Supporters

---

**DEMENTIA AND THE INVISIBLE CAREGIVER**  
[Location, Story]

Young caregivers often face social isolation and guilt when having to care for a parent or grandparent with dementia. If you are a young caregiver going through this journey, please know…

---

**KEEP IT INCLUSIVE, SIMPLE AND SAFE THIS HOLIDAY SEASON**  
[Location, Story]

Busy, loud and full of cheer with lots of hugs and smiles to go around. Redemptions are always lovely occasions where everyone comes together to celebrate. Here are some tips…

---

**GRANDMA’S DEMENTIA AND HOW IGNORANCE WAS CERTAINLY NOT BLISS**  
[Location, Story]

Joanna Sun, from Singapore, shares her memories growing up with grandma and reflects on seeing grandma’s progress through dementia. “As a kid, not knowing any better about dementia, I too did…

---

**Dementia Social**

A Slack Community by Project We Forgot

You are not alone in your journey. Walk with other caregivers and get the support you need. Join the conversation now.

---

**ALZSOCIAL**

A Slack Community by Project We Forgot

You are not alone in your journey. Walk with other caregivers and get the support you need. Join the conversation now.

---

**DEMENTIA: THE HARDEST BUT THE MOST BEAUTIFUL TIMES WERE WHEN THOSE WERE CLIMACTIC OF HER FORMER SELF**  
[Location, Story]

[Author, Location]

Both born and raised in America, Carina Mok was always traveling back to Japan to visit her grandparents. She documents her grandmother’s losing her final stages and shares what it was like experiencing…

---

**MOM’S DEMENTIA AND MY JOURNEY TO ACCEPTANCE**  
[Location, Story]

[Author, Location]

“ Whatever is present are the right people. Whenever it begins is the right time. Whatever happens is the only thing that could have happened. And when it’s over, it’s over…”

---

**THINK YOUR LOVED ONE HAS DEMENTIA? TIPS WHEN TALKING TO YOUR GP**  
[Location, Story]

[Author, Location]

With all the education on dementia, it is also easy for a lot of people to jump the gun and assume that their loved ones have dementia when it could…

---

**MY FATHER, THEN AND NOW**  
[Location, Story]

[Author, Location]

Born in India and now based in Seattle, Arjun Kumar is a 31 year old software engineer and filmmaker. His father was diagnosed with dementia in 2011. He looks back at his father’s life and…

---

#PWFALZ

@PROJECTWEFORGOT
As of April 2017

**On Web /projectweforgot.com**

- **Sessions**: 13,234
- **Users**: 10,167
- **Pageviews**: 28,991

<table>
<thead>
<tr>
<th>Country</th>
<th>Sessions</th>
<th>% Sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>4,059</td>
<td>30.67%</td>
</tr>
<tr>
<td>Singapore</td>
<td>3,666</td>
<td>27.70%</td>
</tr>
<tr>
<td>India</td>
<td>2,666</td>
<td>20.15%</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>708</td>
<td>5.35%</td>
</tr>
<tr>
<td>Canada</td>
<td>282</td>
<td>2.13%</td>
</tr>
<tr>
<td>Australia</td>
<td>177</td>
<td>1.34%</td>
</tr>
<tr>
<td>United Arab Emirates</td>
<td>127</td>
<td>0.96%</td>
</tr>
<tr>
<td>Israel</td>
<td>122</td>
<td>0.92%</td>
</tr>
<tr>
<td>Malaysia</td>
<td>116</td>
<td>0.88%</td>
</tr>
<tr>
<td>Germany</td>
<td>99</td>
<td>0.75%</td>
</tr>
</tbody>
</table>

- **Female**: 68.2%
- **Male**: 31.8%

**Top 3 Age Groups**

- 25 - 34: 38.41%
- 35 - 44: 21.69%
- 18 - 24: 11.58%

Data pulled from Analytics

**On Social Media / Instagram**

- **Followers**: 3040

**Top Countries**

- United States
- United Kingdom
- Canada
- Singapore
- Australia

**Top Cities**

- Singapore
- New York
- London
- Chicago
- Los Angeles

**Female**: 79%

**Male**: 21%

**Top 3 Age Groups**

- 25 - 34: 38%
- 35 - 44: 22%
- 18 - 24: 17%

Data pulled from Instagram
STORY CONTRIBUTIONS AND BUILDING COMMUNITIES GLOBALLY:

Outreach Through
- Social Media & Digital Platforms
- Cross Partnerships with Communities targeting younger age groups

Direct Sharing & Communication
- Email Interviews
- Face-to-Face Meetings
- Skype Calls
- Social Media Messaging

Feature Story on projectweforgot.com
- For audience to share their story on the platform, we would need at least 2 pictures

Stigma and the fear of stepping out
- Judgement from friends, colleagues or employers hinder the sharing by audience

Australia  Japan
Canada   Malaysia
Hungary  Singapore
India    UK
Israel   U.S.
I don’t feel comfortable sharing my story and putting my face out there because I don’t want my friends in school to find out. **No one in school knows so maybe it’s easier to keep it that way.**

I don’t want to have to start explaining to everyone who have read my story what is happening at home. I know **they are going to start asking questions** out of concern… but I don't have the ability to handle that right now.

I thought I was ready to share but maybe not right now. I am in the midst of switching jobs and **I don’t want my prospective employer to chance upon the article.** More needs to be done to help support the younger community of caregivers, for them to feel empowered to step out.
Dementia Outreach, Awareness and Supporting Young Caregivers

Younger Public Audience

Younger Caregivers

Outreach & Awareness

Scraping the surface but getting word out there
Get social with the aim of helping the younger community to be aware of dementia and the impact on PWDs + Caregiver

Knowledge & Education

Going deeper
Structured guides aimed at educating the younger community and key persons: students, colleagues, teachers and employers

Support

To support peers, colleagues, teachers and employers know what to offer

To be supported
Access to support resources. Know what to ask for

Empowerment

Awareness, Understanding + Support =
Possible empowerment to step out to share and help inspire others in the community

Targeted messaging across each stage

#PWFALZ

@PROJECTWEFORGOT
Targeted messaging to reach out to the younger community

Millennials = Generation born between 1980 - 2000

Characteristics

- Short attention span
- Dislike traditional marketing
- Appetite for collaboration, to be involved
- Constantly digitally connected
- Learn and align themselves with brands that reflects the image they wish to convey about themselves

Engagement

The importance of branding, tailored campaigns, engaging content

Be Relevant, Authentic and Personal
Understand and connect at their level. Find them on platforms they use

Create Experiences
The importance of story telling and building a community

One size does not fit all
It is important to tailor look, feel and customisation of programmes and services

#PWFALZ
PROJECT WE FORGOT (PWF) / OFFLINE CHAPTER ACTIVATIONS (SINGAPORE)

Singapore:
1. Outreach Events
2. Support Activities

Offline local chapter activations

local outreach activation

The Step Up, Speak Out! Series:

Quarterly in 2017
- April
- August
- December

local support activities

The Caregiver’s Mixer July 2017

Support activities targeted at the younger caregivers (ages 39 and below) - include youth/students and young working adults.
Working with a global network to gather insights + design workshops & programmes

Global collaborations & partnerships

Survey & research work

Alzheimer’s Disease International (ADI)
Global Review on Young Caregiver Services
A scoping review to understand the services defined for young caregivers offered by ADI Member Associations.
Results out in May 2017

Global Young Caregivers Survey
The next step after the global review with ADI: to understand the needs, wants and pain-points to design programmes and services for the target group.

Consulting Projects:
Product or Programme Development targeted for the younger community
help support us.

start your local chapter:
- younger individuals are reaching out to us for help and it would help to know that we can point them to a local chapter or rep that can help and support them!

knowledge transfer:
- share insights
- feedback on current relevant programmes
- help spread the word about the work that we do

funding:
- help us hire a team of individuals who have been/are caregivers to forward the impact and the work that we do
- help fund our local outreach event activations and support mixers

collaboration & partnerships:
- consulting projects
- media, online and event collaborations to help reach the younger community
Thank you & join us

Reach out to find out more about how you can be involved in helping to support the younger community of caregivers and the work that we do.

Melissa Chan, Project We Forgot / Singapore
melissa@projectweforgot.com