# DEALING WITH IT MYSELF

DEALING WITH IT MYSELF
SUPPORTING CALD WORKING CARERS

MULTICULTURAL
CENTRE FOR
WOMEN'S HEALTH

This report details the main findings of *Dealing with it myself,*
a two-year project run by MCWH to support immigrant and refugee carers.

**MULTICULTURAL**
CENTRE FOR
**WOMEN'S HEALTH**

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SUPPORTING CALD WORKING CARERS

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## ACRONYMS

| | |
|---|---|
| ABS | Australian Bureau of Statistics |
| BHE | Bilingual Health Educator |
| CALD | Culturally and Linguistically Diverse |
| CEPAR | Centre of Excellence in Population Ageing Research |
| CHSP | Commonwealth Home Support Program |
| DoH | Department of Health |
| DSS | Department of Social Services |
| ECCV | Ethnic Communities Council of Victoria |
| FECCA | Federation of Ethnic Communities' Councils of Australia |
| GP | General Practitioner |
| HACC | Home and Community Care |
| MCWH | Multicultural Centre for Women's Health |
| NARI | National Ageing Research Institute |
| NDIS | National Disability Insurance Scheme |
| SMRC | Southern Migrant Resource Centre |
| OECD | Organisation for Economic Cooperation and Development |
| WHO | World Health Organisation |

## A NOTE ON TERMINOLOGY

The terms 'carer' or 'caregiver' can refer to either unpaid informal carers or paid care support staff. In the present report, the terms refer exclusively to unpaid informal family carers of an elderly person and/or a person living with a disability or chronic or mental illness. While the Australian literature tends to employ the term 'carer', much of the North American literature uses 'caregiver'. We use carer and caregiver interchangeably, usually reflecting the literature being cited.

The term 'hidden carer' refers to people who are in a caring role, but who do not self-identify as carers or who are not recognised as carers by professionals and their communities.

# ACKNOWLEDGEMENTS

## ACKNOWLEDGEMENT OF COUNTRY

MCWH acknowledges and pays respect to the Wurrundjeri people of the Kulin nation, on whose land this report was written.

We recognise that as immigrants to this country, we also benefit from the colonisation of the land now called Australia and have a shared responsibility to acknowledge the harm done to its first peoples and work towards respect and recognition.

We pay our respects to Aboriginal and Torres Strait Island peoples, their ancestors and elders, both past and present and acknowledge their continuing connection to land, sea and community. We hope our work contributes to the wider project of cultural respect and recognition in Australia.

*"Without carers, the healthcare system would be overwhelmed. GPs would be booked months in advance, hospitals would be bursting at the seams, and aged care facilities would be struggling to keep up with demand.*

*Without carers, the community care system would also be overwhelmed. People living in their homes would need round-the-clock support for feeding, showering, dressing, and managing money, medications, and household maintenance."*

Researcher Siobhan O'Dwyer (2016)

## MCWH ACKNOWLEDGEMENTS

# EXECUTIVE SUMMARY

This report details the main findings of *Dealing with it Myself*, a two-year project run by the Multicultural Centre for Women's Health (MCWH) between 2015 and 2017 to support immigrant and refugee carers. The project was funded by the Australian Government, under the Aged Care Service Improvement and Healthy Ageing Grants scheme.

Informal carers support family members or friends who are frail elderly, and/or living with a disability, chronic illness or mental illness. Demand for informal caring in Australia is projected to rise as our population ages, particularly within immigrant and refugee families, who have an older age structure than the Australian-born population. [1]

The ageing immigrant and refugee population experiences substantial barriers in accessing services, due to intersecting factors such as limited English proficiency, social expectations about family-based elder care, and little understanding amongst service providers about culturally appropriate aged care. With limited ability to navigate the aged care system and personal preferences for 'ageing at home', older migrants rely more heavily on family members than the Australian-born elderly, and research has identified a need to provide greater support to informal immigrant carers in order to promote healthy ageing amongst an increasingly diverse population (FECCA 2015).

For *Dealing with it myself*, we worked with immigrant and refugee carers to research, co-design and develop bilingual resources and health education on carer support and wellbeing for families from Arabic, Burmese, Chinese, former Yugoslavian, Hakha Chin, Indian, Karen and Punjabi backgrounds.  Participants were in a variety of caring roles, caring for elderly parents, spouses with a chronic illness and family members living with a disability.

We found that cross-cultural understandings of 'caring' vary significantly, contributing to low carer self-identification within immigrant and refugee families, and challenges in understanding and navigating the health and support system.

We also found that caring is highly gendered across all cultural contexts, informing both policymakers' and families' expectations about who in our community is available and willing to care in the current shift away from institutionalised care to 'community-based care'. Across all communities and families in Australia, women are overwhelmingly meeting the rising demand for informal care. Given the lack of high quality, culturally appropriate and accessible support services, immigrant and refugee caring families face particular barriers in meeting and planning for their families' current and future care needs.

The Australian Government now recognises that early intervention is crucial to maintaining carer health and wellbeing and reducing healthcare costs (DSS 2017). We recommend the following actions in order to reduce inequitable health outcomes and improve access to services for immigrant and refugee families:

- Sustainably funding ethno-specific and multicultural health services;

- Delivering culturally-tailored community health education;

- Removing barriers for accessing support services;

- Training social welfare and healthcare staff in cross-cultural awareness and identifying hidden carers; and

- Conducting high quality participatory research.

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[1] *ABS 2017:*
*http://www.abs.gov.au/ausstats/abs%40.nsf/mediareleasesbyCatalogue/5E54C95D3D5020C6CA2580FE0013A809?OpenDocument*

## THE MULTICULTURAL CENTRE FOR WOMEN'S HEALTH

The Multicultural Centre for Women's Health (MCWH) is the national voice for immigrant and refugee[2] women's health and wellbeing.

MCWH is a Victorian women's health service established in 1978. We work both nationally and across Victoria to promote the health and wellbeing of immigrant and refugee women through advocacy, social action, multilingual education, research and capacity building.

We have a strong track record of delivering health education to marginalised communities, employing a multilingual, participatory approach to education. Our bilingual health educators (BHEs) deliver sessions in an outreach capacity, 24 hours a day, 7 days a week. MCWH is one of the very few organisations across Australia specialising in the provision of health education training for bilingual and bicultural workers and the delivery of multilingual education to immigrant and refugee communities. Through this work, we have developed ongoing working relationships with community organisations and community leaders; as well as a detailed understanding of the barriers immigrant and refugee women face in accessing health care in Australia.

## THE *DEALING WITH IT MYSELF* PROJECT

*Dealing with it myself* is a unique 2-year project conducted by MCWH from 2015 to 2017, to support and raise awareness about carers and working carers from five immigrant and refugee communities: Arabic, multicultural Burmese (including Karen and Chin), Chinese, former Yugoslavian and Indian (including Punjabi).

The project engaged communities that traditionally have had little access to ethno-specific support or information. Using culturally-tailored narrative approaches, we have recorded carers' stories via focus groups and interviews, identified carers' information support needs, developed multilingual resources, delivered community education sessions, and helped to establish carer and family support groups so carers are empowered to support themselves and each other in managing multiple responsibilities.

### Background of the problem & importance of the project

Australia's population, like that of other Organisation for Economic Co-operation and Development (OECD) countries, continues to age due to the combination of greater life expectancy and the onset of old age for the 'baby boomers'. According to the 2011 Census, nearly 20% of Australians over 50 were born overseas in a non-English speaking country (FECCA 2015). Importantly, the overseas-born population has an older age structure than the Australian-born population, with 18% of people born overseas aged 65 or over, compared with 12% of people born in Australia. Overall, approximately 30% of people providing or requiring care in Australia come from an immigrant or refugee background (Taylor 2013: 29).

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[2] *The term 'immigrant and refugee' refers to people who have migrated from overseas, and their children. It includes people who are a part of both newly emerging and longer established communities, and who arrive in Australia on either temporary or permanent visas. In this report we use the term CALD when citing other literature.*

The higher prevalence of chronic illness among older age groups, in particular dementia and associated disability, increases the need for informal caring. Australia is currently experiencing a community-led and government policy trend to shift care from formal institutionalised care towards community-based and informal family care. In many ageing immigrant and refugee communities, due to culturally inappropriate service provision, family circumstances and language barriers, the burden of informal caring often falls on women family members, caught between generations, many of whom have multiple caring responsibilities, including children, grandchildren and paid employment.

An extensive body of literature indicates that carers suffer from higher than average rates of physical and mental health problems, particularly when they are undertaking their caring role with low levels of family, community and formal support. Immigrant and refugee seniors and carers in particular have smaller family networks and lower rates of service use compared to the Australian-born population, potentially placing strain on caring families and leaving complex health needs unmet (Cash et. al. 2013; CEPAR 2014 B; FECCA 2015; and Team et. al. 2007). Through *Dealing with it myself* we have supported caring families by developing and delivering culturally-tailored multilingual health information on available support services, and raising awareness about carer health and wellbeing amongst family and community members.

## Project aims, objectives & outcomes

The key aims of *Dealing with it myself* were to improve the physical health, psychological wellbeing and social connectedness of immigrant and refugee carers by developing and distributing multilingual resources, delivering peer education sessions, and piloting carer and family support groups.

The specific objectives of the project were as follows:

1 **Multilingual Resources:**
   Developing and distributing multilingual resources on the basis of a literature review, stakeholder consultations, and focus groups and interviews with immigrant and refugee carers from five target communities.

2 **Multilingual Community Education Sessions:**
   Delivering multilingual peer education sessions to carers and family members from five ethno-specific communities. Sessions were delivered to the general community in order to reach 'hidden' carers, as well as to generate support and understanding for carers amongst their care recipients, family members and peers.

3 **Culturally-Appropriate Peer Support Programs:**
   Forming community-based carer and family support groups, to explore culturally-resonant concepts of self-care and introduce members to services which can support their families in their caring roles.

*Focus group with Chinese carers, 2015*

In order to meet these objectives, we conducted the project in three phases:

## PHASE 1:
## CONSULTATION AND RESEARCH

During Phase 1 we conducted a literature review (covering both academic and grey literature), consulted fourteen stakeholders with experience and expertise in immigrant and refugee carer support and ageing (see Appendix B), convened two project advisory group meetings and conducted interviews and focus groups with forty-seven carers in total (thirty-nine female and eight male carers).

## PHASE 2:
## BHE TRAINING AND MULTILINGUAL RESOURCE DEVELOPMENT

Research and consultations conducted in Phase 1 informed the *Dealing with it myself* BBHE training manual for delivering health education, which covered four modules:

1   Who are carers or working carers?
2   The impact of multiple roles.
3   Challenges faced by immigrant and refugee carers.
4   Strategies in dealing with challenges.

After we developed the modules and training manual, a one-day training session on carer support and community awareness was provided to our team of twenty BHEs, covering the five ethno-specific communities targeted in the project, as well as eleven others. We decided to train and up-skill our entire BHE team so the project can be extended to other ethno-specific groups in the future.

We also produced and distributed three resources designed for immigrant and refugee carers and their families:

- *Being a Carer in Australia* (available in Arabic, Burmese, Chinese, Croatian, English and Punjabi)
- *Caring for Myself* (available in Arabic, Burmese, Chinese, Croatian, English and Punjabi)
- *Carer Information Factsheet* (available in English)

## PHASE 3:
## COMMUNITY HEALTH EDUCATION AND PEER SUPPORT

Our BHEs delivered forty-nine community education sessions and one Chinese radio session over the course of the project to the five target communities, including three mixed multicultural groups. In total, we made contact with 867 community members through our sessions (not including the radio program).

We formed two support groups for Chinese and Punjabi carers and their family members in close consultation with members, and facilitated activities chosen by them to promote a sense of improved social connectedness, respite ('having a break') and physical and emotional wellbeing. During activities, we provided health information and help in connecting to services, so carers, care recipients and family members have ongoing formal support or knowledge about accessing services if the need arises in the future.

Evaluation from participants of both the community education sessions and peer support groups indicate that the project successfully:

- Increased awareness amongst immigrant and refugee families of the physical, psychological and financial impacts of caring;

- Increased access amongst immigrant and refugee carers to culturally and linguistically relevant support services and timely information;

- Increased understanding of available support systems for immigrant and refugee carers, and their care recipients and families; and

- Increased participants' willingness to use support services in the future and participate in activities which improve their physical health, psychological wellbeing and social connectedness.

As a community health promotion project, *Dealing with it myself* was co-designed and delivered in close consultation with community organisations and immigrant and refugee carers and families. This approach reflects MCWH's participatory, intersectional feminist framework; which recognises immigrant and refugee women as experts in their own health, while also addressing the social determinants of health and the structural barriers women face in accessing services.

We sought community and stakeholder feedback at each stage of the project, from deciding which five ethno-specific communities to engage (involving broad community and stakeholder consultations) to deciding the best way to identify, recruit and consult carers, develop multilingual resources, and facilitate community education sessions and peer support groups.

## CONSULTATIONS WITH STAKEHOLDERS

We engaged stakeholders through consultations and the Project Advisory Group. Members of the Advisory Group, listed under Appendix A, contributed many years' experience and expertise in the fields of carer support and immigrant and refugee health and settlement. Their input and advice greatly informed the changing focus and methodologies of the project.

While we invited a number of carers and community organisations onto the advisory group, due to funding, time and transport constraints, carers and staff at community organisations preferred to be consulted individually. Unfortunately, this reflects the current health and community services funding environment in which ethno-specific and smaller community-based organisations have had their funding reduced relative to mainstream organisations, leaving them with less staff and resources to meet ever-growing community needs.

Our BHEs were invaluable in providing and seeking carer and community feedback, as well as providing feedback during the development of multilingual resources in their capacity as trained bicultural health educators. We therefore attempted to consult a wide range of professionals and community members throughout the project, in a manner that allowed them to participate and allowed us to revise various aspects of the project in response to community needs.

## CONSULTATIONS WITH IMMIGRANT & REFUGEE CARERS

In the original project plan, we proposed to conduct two focus group sessions each with carers from our five target communities (that is, ten focus group sessions in total).

Focus groups produce excellent discussion and can be an efficient way of conducting research in terms of resources and staff time. However, we modified our approach in response to carer and stakeholder feedback because the set scheduling of focus groups can exclude carers from research if they need to reschedule at short notice.

Interviews offer more flexibility, and can be conducted over the telephone or at carers' homes at a time that suits them, and importantly, can be rescheduled if need be. Although they are more resource-intensive, interviews allow us to reach more socially-isolated and time-poor carers. After consulting with carers and our BHEs we conducted focus group discussions with Chinese and Karen carers (two focus groups each), and individual interviews with Arabic-speaking, former Yugoslavian and Indian carers.

All interviews and focus groups were conducted in-language and recorded and transcribed in English by the relevant BHE. During focus group sessions, we discussed topics by theme, allowing participants to respond to each other's stories and ideas. During interviews carers explored our themes by sharing aspects of their individual story in a more holistic manner. However, we covered the same themes with both interview and focus group participants. Such flexibility in our research methods was vital to completing the research phase of the project and successfully engaging carers from immigrant and refugee backgrounds.

We could not have conducted our carer consultations without the expertise and commitment of our BHEs, who drew on their community networks to recruit carers. This was important as we did not exclusively rely on carer service organisations to recruit participants, meaning we reached 'hidden' carers who were not necessarily accessing formal support services.

## DELIVERY OF THE PROJECT: COMMUNITY EDUCATION

During the planning phases of the project, we proposed to support CALD working carers, that is, immigrant and refugee women and men who are in a caring role while simultaneously maintaining paid employment. While the project continued to support working carers, during implementation we broadened the scope to include non-working carers and their families, taking a whole-of-community approach to health education and raising awareness and understanding about the impacts of the caring role amongst community members more generally. We made these changes in response to data in the literature review, and advice from service providers and immigrant and refugee carers who participated in our consultations.

The principle of prevention, key to health promotion, strongly informed our holistic approach to the delivery of multilingual community education sessions. Due to our ongoing relationships with community groups, community health centres, women's groups and ethno-specific organisations across Victoria, MCWH is in a unique position to reach a wide range of participants. By delivering carer awareness sessions to general immigrant and refugee community groups, we reached 'hidden' carers, as well as future carers and friends and family members of carers. Such a holistic and preventative approach to awareness-raising recognises that caring occurs within a wider web of relationships between family and community members who, when equipped with an understanding of the challenges of the caring role, can support carers and care recipients. As one female participant put it:

*I enjoyed learning about the difference between a working carer and a non-working carer. This has made me think that I don't want to give too much pressure to my daughter for taking me to medical appointments or grocery shopping. After the session I will consider applying for a formal service.*
Female care-recipient, Chinese education session

Literature and evidence on facilitating supportive care relationships substantiates this broad community education and outreach approach.

Healy (2008) has stated that carers are "ethical subjects who operate best in *a network of collective recognition and support*" (*ibid*: 2; emphasis added). They are not 'static subjects' but rather are transformed by the labour of caring. Whether this transformation is life affirming or physically destructive depends upon their social and economic circumstances (*ibid*). Addressing the topic of carer support at a broader level, Healy writes that healthcare reform should aim to create social conditions that allow carers to demonstrate "ethical fidelity" to their care recipients (*ibid*: 6-7). Public awareness of the value of informal caring, of both its rewards and its challenges, is vital in creating such supportive social structures (*ibid*). *Dealing with it myself* operates within the ethos of such recommendations – acknowledging and working with carers' own understandings of their roles and experiences while offering in-language health education on available support services and raising awareness about the value and challenges of informal caring amongst members of the five target communities more broadly.

It is important to note that we proceeded cautiously with this conversation, particularly with elderly participants of our education sessions, as the notion that eldercare can cause stress to adult children is a sensitive one. This is where our narrative-based and peer-led approach allowed bicultural educators to skilfully facilitate delicate conversations around gender roles, eldercare, family obligation and avenues for seeking help in Australia.

As one BHE put it:

*The participants were most interested in the physical, emotional and financial impacts of caring. They said that even though these thoughts had come into their minds previously, they were running away from them as they didn't want to challenge family responsibilities and values.*

*I noticed hesitation initially in a couple of the participants. One of them said his [adult] children take care of him and his wife very well so he was not finding any worth in this session. But he became interested later on. Another man said it is not ideal to be discussing this in a group as we don't want to move away from family values. I handed the conversation over to the audience who explained to him that this session is in no way affecting their respect for family values.*
MCWH BHE, evaluating a Punjabi education session

## DELIVERY OF THE PROJECT: PILOTING CARER & FAMILY SUPPORT GROUPS

The final major revision for our project was in the area of peer support. Originally, we proposed to conduct two peer support group sessions with carers from each of our five target communities; and to support groups to continue meeting after the end of the project. However, our advisory group members and key stakeholders cautioned that it would be difficult to ensure carers are sufficiently supported to continue the group after only two pilot sessions. Peer support, as workers in the community health sector know, requires a solid model, with trust and rapport built between workers and members over a prolonged period, and ongoing support needed in relation to transport and respite. A traditional model of peer support, as organised by health workers, is a specifically western cultural health practice. We certainly acknowledge that peer support models can be culturally-tailored, but this required significant time and resources that were outside the limits of our project. Following advice from stakeholders, we were concerned about establishing peer support groups and asking them to self-sustain knowing that we could only offer periodic (but not sustained) support once the project was completed.
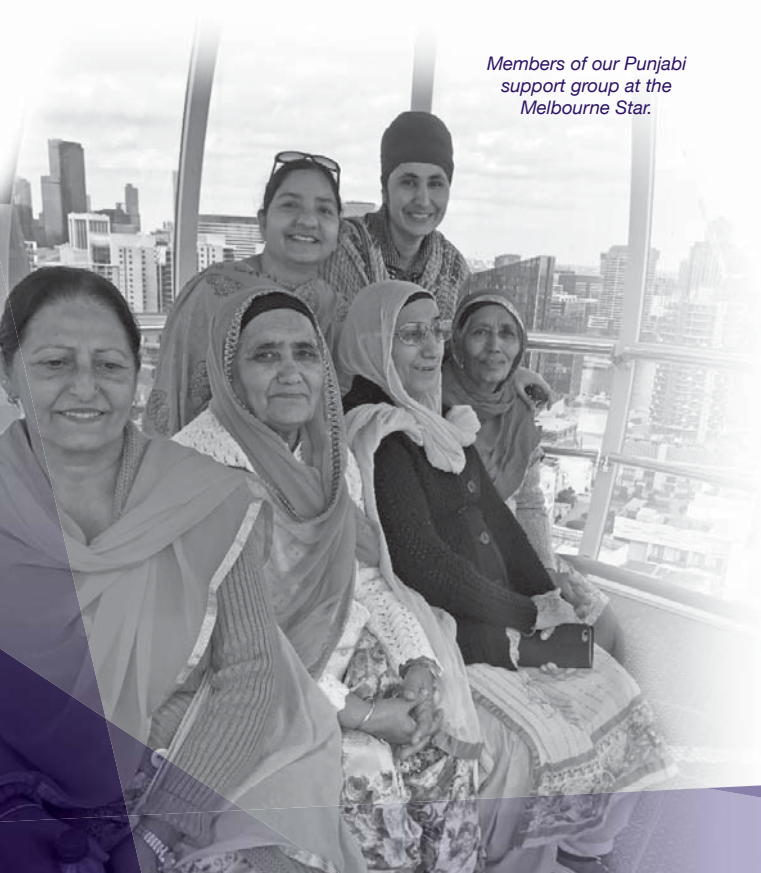
Most importantly however, our BHEs asked extensively during interviews, focus groups and education sessions whether carers would be interested in our peer support program, and the majority of carers stated that they simply do not have enough time.

We therefore modified the peer support program and worked with families from two of the five communities who expressed interest – Chinese and Punjabi. For the Chinese peer support group, we recruited carers from education sessions, and worked closely with them to co-design a program of culturally tailored activities. Feedback was overwhelmingly positive, with most carers indicating at the end of the program that they are now open to using respite or similar support services:

*I had believed that carers should not think of caring for themselves as this shows a level of selfishness which is incompatible with the ideas of our culture. But today I came here without my daughter, and I found that a short time away from my daughter to do things I enjoy has actually made me feel more energised and alleviated feelings of exhaustion. I now feel better able to care for my daughter.*

Female carer, Chinese support group

*I felt relaxed because my husband was with me. When the facilitator told me the session was for carers I initially was a bit reluctant to join, because I don't like leaving my husband alone and I don't use a respite service. The facilitator then said my husband is welcome to join and I was really happy.*

Female carer, Chinese support group

For the Punjabi peer support group, we recruited participants from the Lynbrook Sikh Temple who had very little previous contact with support services. Carers requested that we establish a family support group, allowing older female members (carers and care recipients) to come together and connect during social outings.

As this group of women were only available on the weekends, we ran three longer Sunday sessions, involving a visit to the Shepparton Sikh Temple, the Melbourne Star and Gumbaya Wildlife Park.



*Members of our Punjabi support group at the Melbourne Star.*

Again, feedback from the group was positive, with participants learning about aged care and carer support services, and connecting to each other for ongoing social support.

*I believe our bodies may have made two kilos of extra blood today, for the amount of laughter we had during the trip!*

Female participant, Punjabi support group. Her quote relates to a popular Punjabi saying: Whenever someone is too happy or laughs too much, their body makes extra blood, meaning that their body has become healthier through happy moments.

*I feel confident in sharing my life experiences and difficulties with the members of this group now. I know there will be someone to help me out if I need them one day, I just need to express myself and talk to them.*

Female participant, Punjabi support group

After these three sessions, we held an additional health education session with the group, encouraging their adult children and carers to attend. The success of the Punjabi support group demonstrates the importance of co-designing flexible programs that build rapport with participating individuals and families, respect carers' wishes regarding how they wish to be supported, and are tailored to the needs of each particular community. The pilot also demonstrates the importance of ongoing funding and support for groups to be sustainable.

## PARTICIPATING COMMUNITIES

In order to decide which communities to include in *Dealing with it myself*, we consulted a wide range of people and sources, including statistics on immigrant ageing patterns in Australia, relevant literature, and of course carers, community leaders, BBHEs and stakeholders.

We chose to work with the following five immigrant and refugee communities because of their varied migration and settlement histories (covering groups that are relatively large and established to those that are recently-arrived), and because they represent a breadth of 'intra-community' experiences.

**These five communities are:**

- Arabic-speaking communities
- Chinese-speaking communities
- Former Yugoslavian communities
- Indian and Punjabi communities
- Karen and multicultural Burmese communities

For instance, 'Arabic-speaking' covers a broad range of communities and dialects, with migration waves starting from the 1970s to families who have arrived more recently on humanitarian visas due to the wars in Syria and Iraq. Arabic is also widely-understood by other Middle Eastern communities (e.g. Assyrian and Chaldean speakers) and including the language thus broadened the reach of our education sessions and resources.

Former Yugoslavian languages include, broadly, Bosnian, Croatian, Macedonian and Serbian. As with Arabic-speaking communities, migration waves from the former Yugoslavia have a long history, from post-WWII migration to humanitarian migration due to the conflict in the 1990s. Similarly, the labels 'Chinese' and 'Indian' cover a broad range of dialects, language groups and migration experiences, while representing two of the fastest-growing migrant communities in Victoria (and nationally).

Finally, we included the Karen community in order to reach a smaller, new and emerging community which is often excluded from community-based research, and to understand the specific challenges they face.

Community leaders and stakeholders advised us that many Karen families, who have arrived on humanitarian visas, have elder-care responsibilities, and this was certainly substantiated by the Karen carers we consulted. Unfortunately, mid-way through our project our Karen BHE left our employment. From this point, we conducted sessions via an interpreter, and opened them up to other Burmese-speaking communities, including Hakha Chin carers. We therefore translated our resources into Burmese rather than Karen.

## WHO ARE CARERS: EXPLORING CROSS-CULTURAL DEFINITIONS

### Interpretations of caring: literature & policy

Comparisons of academic, policy and grey literature, as well as cross-cultural perspectives on caring and kinship, reveal diverse understandings, definitions and interpretations of the term 'carer'. In the Australian aged and disability sector, informal carers are understood to be people taking care of an elderly person or a person living with a disability, mental illness or chronic illness, or those who are dependent on alcohol or drugs.

Government and non-government organisations use differing definitions of the term 'carer', which can impact upon carers' eligibility for services. For instance, while some carers might not qualify for Centrelink payments, they might qualify for services from non-government carer support organisations who operate with different definitions. (See right column for these definitions.)

Writing from a service-provision perspective, Cardona et. al. (2005: 10) have noted that the formal term 'carer' emerged in the mid-1970s in Australia, "attempting to redefine what was previously understood as a private family relationship into a distinctive set of roles, responsibilities and rights: a social contract between the carer, the care recipient and health and community care agencies". Nonetheless, there are inconsistencies in this social contract, with many carers denied access to services, and service providers prioritising people without informal carers.

Moreover, the existence of income- and means-testing for carer support payments indicates that caring is understood in the policy context to be a family responsibility, rather than being actual work deserving of compensation regardless of the carer's other income and means. As a result, most carers are women on low incomes (*ibid*).

The **Australian Government's** *Carer Recognition Act 2010* defines a carer as: [3]

> an individual who provides personal care, support and assistance to another individual who needs it because that other individual:
>
> (a) has a disability; or
> (b) has a medical condition (including a terminal or chronic illness); or
> (c) has a mental illness; or
> (d) is frail and aged [3]

While not all state and territory laws are based on this act, most operate with similar definitions.

The **Australian Bureau of Statistics (ABS)** defines a carer as: [4]

> a person aged 15 years or over who provides ongoing informal help or supervision to persons with disabilities or long term health conditions, or to persons aged 60 years and over. The help provided must have lasted or be expected to last for at least 6 months. Carers who assist someone in another household are identified on the basis that they provide help with 'everyday sorts of activities' without further specification. Carers who assist someone in the same household are identified on the basis that they provide assistance with one or more of these activities: communication, health care, housework, meal preparation, mobility, paperwork, property maintenance, self care and transport.

In order to qualify for Centrelink payments, carers usually have to live with the person they are caring for, and provide ongoing assistance for at least 6 months.

**Carers Australia** defines a carer as: [5]

> a person who provides unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged.

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[3] https://www.legislation.gov.au/Details/C2010A00123
[4] ABS http://www.abs.gov.au/ausstats/abs@.nsf/7d12b0f6763c78caca257061001cc588/e8b04ea9a311fa45ca25703b0080ccb7!OpenDocument
[5] Carers Australia http://www.carersaustralia.com.au/about-carers/

Indeed, the notion of caring as a (partially) social responsibility and legitimate area of government intervention into family life sits uncomfortably with long standing, popular and cross-cultural understandings of caring as family obligation, private responsibility, or personal sacrifice in gratitude for parental sacrifice; undertaken predominantly by women (Boughtwood and Kourouch 2010; Bryant and Lim 2013; Donovan and Williams 2015; Miyawaki 2015; Lino 2010; Spitzer et. al. 2003; Team et. al. 2007; and Ussher et. al. 2013).

As a result, many carers do not self-identify and thus do not seek services – particularly immigrant or refugee carers who may have moved from regions with very different social norms surrounding family care and government-funded health interventions (FECCA 2015; Stanley et. al. 2013; Sun et. al. 2012; Taylor 2013; and Team et. al. 2007). For instance, none of the female Russian-speaking caregivers in Australia interviewed by Team et. al. (2007) perceived caring as a social role or responsibility that should be supported by the government. As one woman explained, "*I don't view myself as a caregiver. Nobody told me that I am a caregiver. You [the interviewer] are the first who referred to me as for a caregiver*" [sic] (*ibid*: 401).

Caring as a broader social role and government responsibility implies an impersonal relationship (for instance between a government-funded service provider and a care recipient who the government has to support based on universal and abstract principles of citizenship, rather than specific kinship ties), and Team et. al. (*ibid*) argued that women in their study emphasised their familial kinship roles over other identifications. Reflecting cultural understandings of caring and gender relations, there is in fact no word for 'carer' in Russian, with the gender-specific terms 'mother' and 'wife' referring to the roles encompassed by the English word 'carer' (*ibid*).

For many, the term 'carer' is difficult to translate or identify with, as carers resonate more strongly with culturally-meaningful and relational roles such as mother, wife, son, bread-winner and so on. As Cardona et. al. (2005: 11) have stated, "Alternative cultural values understand caring as a continuing and multifaceted relationship, an 'action verb' rather than a descriptive noun." Carer support schemes, which grant rights on individual basis, often reflect ageist Western assumptions about the elderly being a burden, presupposing the caring relationship to be one of dependency rather than mutual support. Such assumptions are demeaning to both care-givers and receivers, and do not reflect the lived experiences of many immigrant and refugee families, who often value relationships of mutual interdependence over Western notions of 'independence' and 'carer burden' (*ibid*).

While caring is seen by many as a familial role, carers also recognise the additional pressures entailed in taking on such responsibilities. Many immigrant and refugee carers do seek informal and formal support if they feel it is culturally appropriate and available (Boughtwood and Wu 2010; and Bryant and Lim 2013). The negative impacts of caring are particularly evident for carers in more intense roles with little social and formal support (Cardona et. al. 2005). The reality of migration (whether forced or voluntary) means that families have less informal support in Australia.

Smaller and denser family networks can sometimes place *more* pressure on primary carers, through monitoring and 'moral policing' of women's behaviour, expectations to maintain strict gender roles, and additional caregiving demands for relative's children (Cardona et. al. 2005; FECCA 2015; and Katbamna et. al. 2004). Any efforts to support immigrant and refugee carers must recognise this diversity of experiences, and invite carers to share their own understandings rather than impose cultural assumptions or stereotypes.

Importantly, the caution some immigrant and refugee communities express towards government interventions in family matters can be related to experiences of structural violence and discrimination.

As one stakeholder put it:

*Many people who come into a country as a refugee or a migrant have distrust for government. Anyone that they perceive to be associated with government, even if you're not, even if you come to them as a community organisation, they see you as really part of the governmental structure... because a lot of them have come from systems where they have been abused, and it's just hard to build that trust.*

We asked *Dealing with it myself* participants to share their own understandings and practices of 'caring' – and their experiences of services – during our focus groups, interviews, health education sessions and peer support sessions. In the following sections, we share their interpretations, stories and perspectives as documented during all phases of the project.

## Interpretations of caring: Immigrant & refugee voices

*But I think that whole concept of a 'carer' as such is a very Western concept. And I think only if we unpack that, and put it back to its normal context... just like parenting; there isn't this whole 'parent' industry. Parenting is normal. So is caring for the elderly and caring for people with a disability. There's just this whole carer discourse and carer industry that's developed, and in many ways it's unnatural, and that's why it doesn't match well.*

Female carer for elderly Indian mother-in-law and husband living with a disability, interviewed for *Dealing with it myself*

*It's difficult every day, because I know it's not going to end. I have to do it every day... It's a dysfunctional family, if you ask me. We are a dysfunctional family. We are coping, we are exhausted, but we are dysfunctional because we cannot do what a normal family does.*

Indian female carer for adult son living with a disability, interviewed for *Dealing with it myself*

As demonstrated by the above two quotes, the carers we spoke to during our interviews and focus group sessions had very different understandings of their role and the term 'carer' itself. Introducing and explaining the project was one of our key challenges when first recruiting immigrant and refugee carers, as there is no direct equivalent of the term 'carer' in many languages.

Our BHEs often used descriptive language (focussing on roles and responsibilities) when communicating the idea of 'being a carer'. Many BHEs noted that translation of the term carer is often gendered, with words such as 'woman', 'wife', or 'housewife' being the closest equivalents. During health education sessions, BHEs asked about and acknowledged participants' various understandings of family caring, before discussing the meaning of the terms 'caring' and 'carer' in the Australian health-system context as a tool to self-identify and access relevant services. [6]

Many participants indicated that the terms 'carer' or 'caring', and the health-sector discourse built around them, did not resonate with their lived experiences or understandings. For instance, one Arabic-speaking male carer, when asked about self-care, responded, "*What do you mean by caring-for-myself?*" Most people spoke of caring for their elderly parents as 'giving back', and as a mark of respect and honour for all the sacrifices their parents have made for them, including helping to care for grandchildren. Karen-speaking participants in particular spoke about caring for the elderly as a blessing, both during the focus groups and education sessions, and expressed concerns about their children "losing this cultural value". Consistent with the findings of the literature review, most participants spoke about caring for the elderly in terms of relationships of mutuality and interdependence, rather than relationships of dependence.

The extent to which families and individuals accepted caring as 'normal' or 'natural' was informed by the intensity of the role. The intensity of caring roles varied greatly amongst project participants, ranging from helping elderly parents once a week with household duties; to looking after all personal and household daily activities for a person living with a disability (including feeding, showering, help with movement and mobility, housework and advocacy with health services) while also caring for elderly parents and managing other child raising responsibilities.

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[6] *Indeed, even in Australian-English health-speak, the term carer can refer not only to informal family caregivers, but also paid care support workers and parents or guardians of children.*

As noted during our stakeholder consultation with Carers Victoria, experiences of caring vary greatly between families according to the age and health of care recipients. For instance, a parent of a child with a mental illness facing institutional and social stigma and navigating the mental health system faces very different challenges from an adult woman caring for her elderly parents and navigating the aged care system.

Participants were more likely to describe caring for ageing parents or spouses as a 'normal' and almost inevitable (yet nonetheless challenging) stage of life as they age themselves.

The following quote from a Bosnian woman we interviewed is typical of the ambivalent sentiments expressed by many carers in our study.

*I became a carer to my late husband. He got sick, bowel cancer, and I just fell into that role without even thinking twice about it.*
Bosnian female carer interviewed for *Dealing with it myself*

Parents caring for a child living with a disability did not describe their caring responsibilities as an inevitable life stage. They often described their caring experiences as outside the 'normal', as they were constantly worried about who will care for their children when they could no longer maintain their caring role.

Importantly, while many participants spoke about caring for a family member as 'normal' or 'natural', they also spoke about the many challenges, as expressed in the following:

*It was a very difficult time for me and my husband. We did not have any friends or extended family to support us. English language was the hardest thing to understand and learn. After just one year of coming to Australia my husband got very sick, and it was up to me to take care of him as is customary. Where I come from, the role of the wife is to look after her husband or any other sick family member such as elderly parents or children. I maintain all values and customs from the country I come from.*
Serbian female carer interviewed for *Dealing with it myself*

This and similar stories highlighted two key structural barriers immigrant and refugee caring families experience when first arriving in Australia; namely, the lack of multilingual resources and culturally-tailored services, and social isolation. Keeping such structural barriers in mind, we caution against the assumption that immigrant and refugee families resist external help because of a supposed 'cultural' understanding that caring duties are part of daily (female) life and should be kept internal to the family.

Certainly, many carers mentioned that their family members resisted outside help – or, in the case of some elderly care recipients, denied that they even needed help – but this was often due to lack of awareness about services, or concerns (whether real or perceived) that services would be discriminatory and culturally inappropriate. We found however that once access to services is facilitated through relationships with trusted support staff, many families and individuals were willing to accept help. Take for instance, Joanna's story (see Case Study 1, page 29), who was better able to care for her elderly mother once she developed a relationship with a community nurse who could show her how to use relevant support equipment.

## Importance of community understanding & support

There is a deeply gendered politics to the assumption that immigrant and refugee families will accept and assimilate caregiving roles due to 'culture'. Women (whether Australian- or overseas-born) make up the majority of carers in Australia, and as discussed below, the tacit assumption underlying current policy trends towards 'community care' is that women will be available to care. Immigrant and refugee women are layered with additional stereotypes, including the assumption that they will be more willing to care for cultural reasons. The women we spoke to acknowledged themselves that they face cultural and family expectations to take on caring roles.

One female participant in our Karen focus group described for instance how her husband is the 'official' primary carer for his mother (who has dementia), but in practice she spends more time caring for his mother than he does, even though she works part-time while he receives Centrelink carer support payments.

Participants in this focus group noted that women are expected to do "*too much housework*", with housework and caring work overlapping significantly.

This theme emerged in most of our interviews and focus group sessions. One Indian female carer we interviewed advised us to include men in our community health education sessions, so husbands and in-laws understand the multiple pressures women face in terms of caring, housework, employment and child-raising. Another Indian female carer discussed how her in-laws refuse to help care for her adult child living with a disability, adding that she relies "*on the system here*". Her son was well-connected to disability services, and she preferred using formal services to asking extended family for support. During our community education sessions, participants often engaged in detailed discussion about gender roles, and the pressures women face to become carers.

As one male care recipient put it:

*As a non-carer, I really enjoyed the whole session, which allowed me to be reflective as a care recipient. I take for granted my carer who is also my wife. I forget to recognise all her hard work, because I keep thinking of the caring role as a woman's role.*

Male participant, Chinese education session

Cultural stories and values might validate the caring role as a meaningful and honourable one, and are an important entry point into information support for caring families. We encouraged participants to share stories about caring in order to understand and respect their own interpretations and definitions. However, such values – including aspects of Anglo Australian culture underwriting much of the current policy trend towards 'community care' – can also place immense pressure on women in particular to make personal, social and economic sacrifices in order to fulfil caring responsibilities.

Our community consultations indicate that carers are better placed to self-identify and seek support from their immediate family and extended social networks, if their care recipients and families understand the impacts and challenges of the caring role. We therefore engaged a whole-of-community approach to information support, reaching out not only to carers, but also their care recipients and families.

The following feedback from a participant in one of our community education sessions illustrates how BBHEs drew on the lived experiences of carers and their care-recipients to introduce the concept of 'caring' and help participants self-identify:

*The facilitator asked if anyone was in a caring role and none of us raised our hand. The facilitator explained that becoming a carer might involve gradually doing more and more things to help the other person. I started to think that perhaps I am a carer for my husband. My husband used to be independent, but after a few falls I have had to follow him everywhere and help him with showering and toileting. Half way through today's session, my husband said he needed to go to the toilet and I had to go with him. The facilitator pointed this out as an example of a caring role. Today's session has given me a clearer understanding of the carer role and how I might fit into it.*

Female carer, Chinese education session

# THE GENDERED NATURE OF CARE & WORK

## Caring & gender

Unpaid family caring (or caregiving) for elderly adults or people living with a disability or chronic or mental illness is one of several domains of both paid and unpaid caring work in Australia located within a highly gendered work-care regime (Pocock et. al. 2013).

Other domains include unpaid child care and housework related to the care and nurturance of the family more generally; and paid work in the expanding child care, aged care and personal care sectors, and related professions such as teaching, nursing and social work. A number of long-term trends are having a significant impact on women as they manage both paid employment and unpaid household and caring labour (see also Abel and Nelson 1990):

- **Increased female employment:**
  Women continue to participate in paid employment in increasing rates and are working later into their lives as the average retirement age rises;

- **Population ageing:**
  Women are bearing the brunt of the responsibility to care for elderly relatives as the population ages; and

- **Contraction of the welfare state:**
  Demand for women's services in both unpaid caregiving and the formal paid sector is increasing with the privatisation of care work and policy trends towards community-based and 'consumer-directed' care.

Feminist scholars have long argued that women's caring work, whether paid or unpaid, is devalued because of a sexual division of labour which dichotomises and unequally values instrumental 'masculine' activities over affective or emotive 'feminine' ones, such as caring (Abel and Nelson 1990).

In this project, we focused exclusively on the experiences of unpaid family carers of elderly adults or people living with a disability or chronic or mental illness; and more particularly, on the experiences of immigrant and refugee carers in Australia.

While we acknowledge the profound impact of women's (and men's) other responsibilities – including housework, child raising and/or paid care work – the scope of this project centres unpaid family care work as the key responsibility through which to understand carers' health, wellbeing and information support needs.

A feminist lens on the literature allows for analysis of the structural and cultural conditions immigrant and refugee carers face in western host societies, including understandings of informal caring that are often based on white, middle-class values (Cardona et. al. 2005; Fisher and Tronto 1990); the multiple and intersecting layers of marginalisation and disadvantage carers may face on the basis of race, gender, ethnicity, age, class, ability and sexuality; and the gender and familial expectations carers experience within their own families. The deeply gendered nature of caregiving is structurally reflected in both the private and public domains, as women make up the majority of informal (unpaid) and formal (paid) carers. While this report is limited in scope to the experiences of unpaid family carers, it is important to contextualise carers' experiences within broader structural patterns, as these patterns shed light on the underlying gender assumptions about 'women's work' and 'men's work' that inform current policy trends in aged, disability and mental health care. Indeed, such structural-cultural patterns and assumptions partially explain the intransigence of gender inequality, even within the context of gender equality as a policy goal (Pocock et. al. 2013).

Gendered assumptions and expectations about caregiving thus not only determine how the labour of caregiving is distributed within families and how families access informal and formal support; such assumptions also inform social policy, and may intentionally or unintentionally reinforce restrictive gender roles. Writing in the early 1990s, Haaken (1993) argued that feminism did not lead to a significant reorganisation of caregiving within American families. Given that women make up the majority of primary carers in Australia and comparable countries such as the USA, Canada and the UK, it seems that feminism has still not relieved women of the burden of caregiving over 20 years later.

Indeed, the assumptions about carer availability and willingness inherent in policies promoting community care as a cost-effective alternative to residential care, reinforce rather than reform women's gendered role as caregivers (Cash et. al 2013). Minichiello (1997: 453 and 456, cited in Team et. al. 2007: 398) for instance, argued that community care is "an economic policy dressed up as social concern", requiring "family members, and in particular, unpaid women, [to] care at a personal, social and financial cost".

While caregiving is highly gendered work, cross-culturally associated with filial responsibility and parental obligation, it is not an activity restricted to women. Indeed in some of the communities included in the project (for instance, Chinese and Indian), it is traditionally the role of the eldest son to care for parents, although in practice the more personal aspects of care can fall to women in the family (for instance, daughter-in-laws). For this reason, we reached out to both female and male carers, while acknowledging that the majority of unpaid caring work is undertaken by women across all five communities as well as amongst most other immigrant, refugee and Anglo Australian families. While men also become carers, the cross-cultural sexual division of labour relegating 'feminine' activities to the domestic sphere means that caring is both a gendered activity and a gendered experience. Since women are often considered to be the providers of care while men are considered to be the recipients (Spitzer et. al. 2003), the gender of a carer can determine the level of informal (from friends and family) and formal (from medical and other human services) support they are offered.

Both the literature and our consultations indicate that male caregivers are more likely to be given social acknowledgement for transgressing accepted gender roles and for making seemingly higher levels of personal sacrifice. Male caregivers also receive more referrals from health professionals, while female caregivers are generally considered to be better adjusted – with the consequence that women miss out on support services and experience worse health outcomes.

Caregiving by women is thereby naturalised and is not considered worthy of social commendation or additional support (Team et. al. 2007). Studies have consistently found that female carers experience higher levels of distress than male carers, as they are:

- more engulfed in their role;

- more conscious of the emotional wellbeing of their care recipients;

- more likely to experience financial burden and be concentrated in low-wage employment with relatively inflexible working arrangements;

- more likely to juggle competing caring and employment responsibilities, as well as multiple caring responsibilities (including caring for children);

- more likely to experience violence from care recipients;

- less likely to receive social recognition or be offered informal support by their families;

- less likely to be identified as needing formal support by health professionals; and

- more likely to devote more hours to their caring responsibilities than male carers (Gupta and Pillai 2012; Katbamna et. al. 2004; Neufeld et. al. 2008; Team et. al. 2007; Thompson 2007; and Ussher et. al. 2013).

## Caring, gender & migration: exploring the intersections

We have discussed the gendered politics underlying *Dealing with it myself* participants' interpretations of caring above. The immigrant and refugee women who attended our sessions faced unique challenges, including structural barriers to finding employment, long-term financial vulnerability into old age, and being more likely to be engaged in multiple caring and child caring responsibilities with limited social and family support networks.

*It is hard when we have to find aged care for our elderly. They feel we are not responsible enough. That is the worst time for families. We as women first look after our children, then our elderly, how much can we do? We have to make that decision [about aged care] one day. But this decision is not welcomed by the elderly.*

Female participant, Karen education session

Fewer male carers participated in our interviews, focus groups and education sessions. Of those who did, male carers were less likely to be socially isolated, and most stated that their employers were aware of their caring duties and they did not feel that their caring role interfered with their work. However, given the small number of male carers included in our study, we caution against generalising. Stakeholder consultations indicate that both male and female carers experience challenges when seeking workplace support due to dominant gender norms:

*Workplaces view male and female carers differently. For instance, a woman asking for carers' leave might be met with a "not again" response; while a man might be met with an incredulous response. Men can legitimately take time off to coach a sports team, but asking for carers' leave suggests they have no ambition, or have too close a relationship with their parents and so on, and employers wonder why their wife is not available for such responsibilities.*

Stakeholder consulted for *Dealing with it myself*

Many other stakeholders we consulted stated that such gender norms present significant challenges for male carers to step forward and self-identify or ask for help. Nonetheless, and tellingly, the two men in the most intense caring roles in our study were caring for their spouses (and thus their wives could not share the caring role). Men who were caring for elderly parents openly stated that they received much support from their wives, and no men were primary carers for a child living with a disability or mental illness. In contrast, female carers we consulted were in intense roles across all three categories – caring for a spouse, elderly parent or (adult) child living with a disability.

The following quote from a male Macedonian carer illustrates the informal support networks (particularly from wives and mothers) that seem more available to male carers than female carers.

*My wife is more dedicated than me. Thank God. For years and years she was preparing the tablets for my father, for morning, lunch, afternoon and evening. She was preparing them for the whole week, because he had dementia. And my mum was giving the tablets to my father. Sometimes he was reluctant to take them, but my mum was persistent as well – she was like that, that is the nature of my mum.*

While it is important not to generalise within or between communities, particularly on the basis of our relatively small qualitative study, our consultations and evaluations certainly do indicate that the female carers involved in the project experienced higher levels of isolation and familial obligation. Often, gendered expectations about women taking up caring roles prevented general family conversations about how to share the role equitably within the family or with the help of external support services.

Take for instance, the following advice from an Indian female carer who we interviewed:

*The issue with a lot of families is the gender role division. The husband is not supposed to do any housework, so the woman just has the whole load and burden of that. Those are very difficult situations because there is no scope for changing their beliefs. Even from the woman's point of view I've found. It is so ingrained in their mind – that it is their duty as a housewife, to do all the household chores, and the children, and the aged care for everybody living there. And there could always be factors like domestic violence.*

*In India the woman will be taking on all the responsibilities, and she dare not even suggest the husband should contribute to household work. The irony is, if she's the main carer for the mother-in-law, or the parents-in-law, she dare not suggest to the husband that he also share in the burden, because she may then get it [trouble/abuse] from the mother-in-law. You know, this kind of dynamic? And I'm sure here as well it exists in families. Parents have migrated, in-laws have also migrated and living with the families. And it's just...a very unfair situation in terms of that.*

Indian female carer, interviewed for *Dealing with it myself*

Another female carer echoed these thoughts, stating:

*Yes, essentially I think migrants don't realise they're in caring roles. Especially women because there's just an expectation that you'll do it. And I think sometimes that can really catch the women out and they don't realise their health is suffering. And they need to stop and take stock …and realise that's not selfish. Because I think the feeling is…if you do that, it's being selfish. There needs to be education for migrant women who have caring roles. Husbands should be educated that women should be allowed to take a break. Because I think sometimes husbands have that expectation of their wives too, that you take on a caring role and there's no choice about it.*

Indian female carer, interviewed for *Dealing with it myself*

One Serbian woman described how her social isolation presents a significant challenge in caring for her husband (who suffers from depression):

*I expect myself to take full responsibility for my husband's health needs. I did everything for him then and still do now. There's no extended family to help apart from our very young daughter, and she needs help herself because she is only twelve years old. Why it is like this I don't know. It's how I was raised. We have no connections with our community as such and I feel that I have to do everything myself. We feel very alone all the time.*

*I don't feel comfortable talking with anyone about our situation. Whoever finds out about our situation won't do anything for us anymore. Not even a short visit. I never ask for help from anyone.*

*The problem is that I forget about myself. Even my sleep is interrupted and I feel very tired very often. It all depends on how my husband feels. There's no friends to spend time with or family to share our burdens with.*

*The most difficult times are when I do everything in my power to help but I'm then told it's not good enough. Seeing him being angry at me for no reason is the hardest thing someone can experience I think.*

Serbian female carer, interviewed for *Dealing with it myself*

These stories from *Dealing with it myself* interviewees illustrate how the dominant sexual division of labour informs an imbalance of power within caring relationships, which structurally marginalises female carers in particular. Immigrant and refugee carers face additional pressures and domains of disadvantage. In an ethnographic study conducted with Chinese- and South Asian- Canadian female caregivers, Spitzer et. al. (2003) have argued that immigrant women play a key role in the transmission of values which are understood to maintain cultural boundaries and identities. Women are therefore unable to significantly renegotiate their gendered caring responsibilities, despite disrupted family networks, increased demand, and the reality of caregiving with less resources and significant structural barriers to accessing services in their country of settlement. Spitzer et. al. (*ibid*: 270) concluded that caregiving becomes "intensely charged" when conducted in the diaspora, particularly as women also often must find employment to help their families financially.

This intensity of feelings and values surrounding caring were certainly evident in our carer consultations and community education sessions. See for example Sue's story (Case Study 2, page 29), recorded during our Chinese focus group session. This story resonated deeply with all our BHEs, with women acknowledging that renegotiating gender roles can be particularly challenging in the context of intergenerational-migration and settlement. Sue's emotional and financial challenges in being a carer for her elderly parents and a single parent for her two daughters were compounded by structural factors such as being restricted to low-wage employment. During our community education sessions, much of the discussion revolved around gender roles, with some participants highlighting the pressure on immigrant women to engage in both unpaid family caring and paid employment, and the importance of easing such pressures. Others expressed concern about future generations "losing cultural values" by giving less priority to eldercare. As we explore in the following section, caring in the diaspora is further informed by the gendered politics and policies of western host nations, including Australia.

## THE POLITICAL & ECONOMIC CONTEXT OF INFORMAL CARE: 'COMMUNITY CARE' AS PRIVATISED CARE

### Current policy trends

As evident in the above discussion, definitions of 'caring' are closely tied to the social, cultural and political contexts in which its constitutive relationships and activities take place. Australia is currently implementing major policy changes in its aged care, disability care and mental health care sectors, driven by a market-based approach known as 'consumer-directed care'. In principal, this approach provides consumers with choice and control over how resources allocated to them are spent. In reality, immigrant and refugee organisations have concerns about the extent to which marginalised communities and individuals can exercise 'choice and control'. For instance, the negotiation of individual packages in consumer-directed care schemes requires knowledge of the health system and advanced advocacy skills on the part of care recipients and carers. This can be challenging for immigrant and refugee families, and place a particularly heavy responsibility on family members and carers who are perceived to be most fluent in English.

The new approach to service delivery is accompanied by a change in funding models. Whilst services were previously block funded, under the new approach funds are allocated directly to the individual, ideally giving them more choice in the services they chose to engage. In policy parlance, 'consumer-directed care' is also known as 'person-centred' or 'patient-centred' care. Such terminology reflects a second policy trend towards integrated healthcare models, where service provision is coordinated rather than fragmented across community and acute health care settings, and well-sustained by systems to support information sharing (Carter and Morgain 2016).

The My Aged Care and Carer Gateway websites are examples of this new approach to service delivery, and the federal government is currently developing an integrated carer support system (DSS 2016).

The introduction of the National Disability Insurance Scheme (NDIS), rolled out across Victoria from 1 July 2016, and the consolidation of national aged care reforms, are further examples of these policy shifts. Under these reforms, people over 65 who previously received aged care support from the state-funded Home and Community Care (HACC) system will transition to the Commonwealth Home Support Program (CHSP), while people under 65 will gradually transition into the NDIS. Crucially however, temporary visa-holders who qualified for state-funded programs such as HACC are now excluded from the NDIS. Furthermore, changing eligibility criteria has placed great strain on families, as some individuals who qualified for HACC no longer qualify for the NDIS; and HACC eligibility criteria itself has been implemented differently across different local government areas. Some carers in our sessions expressed significant distress about the changing requirements, particularly for those whose care recipients had been refused NDIS packages:

*My husband threatens to kill himself when I am not able to meet his needs. He is only 59 years old and recently was rejected for service by the NDIS. I don't know what to do. I've looked after him for more than 10 years. Last night he said he would like to divorce me. He thinks without me he can manage better. I couldn't sleep last night. He used to have home help, but since we moved to this new area the council said he is not eligible for their service, so I have lived without support for over four years. His care needs have increased a lot in the past two years. He has incontinence and needs assistance with personal care. The facilitator encouraged me to contact my local ACAS to request a Target Group Assessment and hopefully my husband can get approval for home care packages. Without support I do not know how long I can continue in my caring role.*

Female carer, Chinese education session

*At the moment, I can't find any extra activities or programs for my daughter due to the changes with the NDIS. She has been rejected by NDIS, so a lot of activities or services she used to be eligible for have stopped supporting her. I feel frustrated about the changes. Hopefully her school can still provide support to her.*

Female carer, Chinese support group

These stories highlight the immense pressure faced by some carers, compounded by their social isolation and their exclusion from formal support services due to the changing landscape of the aged and disability sector.

Although the current round of aged and community care sector reforms in Australia were initiated in 2012, partially in response to a landmark review into aged care by the Productivity Commission in 2011 (CEPAR 2014 A), the trend away from nursing homes and towards community care has been in motion since the 1980s, when the Commonwealth Government introduced the HACC program to provide more formal services to help people remain at home (Cardona et. al. 2005). As in other OECD countries, the ongoing reforms in Australian aged, disability and mental health care reflect longer-term policy trends towards more consumer-centred, community-based, and independence-focussed models of care which promise greater cost-effectiveness in meeting the needs of an increasingly ageing population (CEPAR 2014 A). The reforms have also been driven by a belief in small government and the view that families are responsible for looking after their own members (Cardona et. al. 2005). Reflecting this, the current reforms in the aged care and disability sectors will mean that carers' eligibility for respite and similar services will be determined by the assessed needs of the care recipient, rather than on the support needs of carers (DSS 2017).

Family carers are thereby positioned inconsistently in policy understandings. On the one hand they are understood to deserve some level of state support because they reduce government spending on institutional care; on the other hand such support is means tested and families are expected to 'look after their own' for as long as they can. Drawing on critical discourse analysis of Australian government policies regarding aged care and caring, Cash et. al. (2013) found that the language of policies directed at 'consumers' or care recipients emphasised individualised values such as 'choice' and 'control', while the language of policies directed at carers emphasise familial values such as 'obligation'. The competing discourses of individualism and familialism promote a market-based, consumer-directed care

approach for care recipients; while simultaneously employing an emotive language about family obligation in relation to carers, thus justifying the push to privatise care as family- rather than state-responsibility (*ibid*).

## The economic contribution of informal carers

Ideological constructions of carers as welfare recipients who are a 'burden' on society resonate strongly in the context of a contracting welfare state. However, far from being socially disadvantaged, dependent recipients of welfare, informal carers contribute significantly to the Australian economy (Team et. al. 2007). Indeed, the policy understanding that community care is more cost-effective than residential care relies on family carers volunteering their time and labour for little or no recompense. In a study commissioned by Carers Australia, Access Economics (2015) analysed data from the 2012 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers as well as more recent sources, to calculate the replacement value of informal care provided in 2015 as $60.3 billion (that is, if all the hours of informal care were replaced with services purchased from formal providers). This is equivalent to 3.8% of GDP and a staggering 60% of the health and social work industry (*ibid*).

## The gendered assumptions of policy makers & impacts on immigrant & refugee women carers

As we have seen, the question of who in the community is able (and presumed willing) to do such unpaid caring work is a highly gendered one, with women continuing to fill the majority of caring roles. There is little understanding of how such community care policies affect immigrant and refugee families, as assumptions that immigrant families have extended networks of kin to call upon for carework are misguided, particularly as strict immigration policies limit family reunion, and as women participate more in paid employment (Katbamna et. al. 2004). Spitzer et. al. (2003) have noted that neoliberal policy and the reprivatisation of carework in the community and home, in the face of cutbacks to government services, create competing caring and work demands for women.

As women earn less than men, they are more likely to leave or reduce employment, although the downward economic pressure on immigrant families can make it difficult for women to leave paid employment altogether. In their Canadian study, they found reduced government spending impacted immigrant women disproportionately, with immigrant women spending longer hours on household and care duties than other population groups (*ibid*). In their Australian study, Cardona et. al. (2005) also concluded that the gendered nature of caring results in women being most economically disadvantaged by their role as primary carer.

The stories gathered in our *Dealing with it myself* focus groups and interviews certainly highlight how immigrant and refugee carers are often isolated and have very few people to call for help, as their social and family networks are much smaller in Australia than in their countries of origin. Moreover, eligibility criteria in the community care market prioritises people with acute care needs and people without family to look after them. Such criteria limit the access of carers, who are usually women, to services which could ease their caring responsibilities and improve their health and wellbeing (Cardona et. al. 2005). This is illustrated in the following and similar stories shared by elderly participants in our education sessions:

*When I ask for help, I am always rejected. They say I have children to take care of me, and I don't need to be given any further support. This is very annoying. I don't know how to get support.*

Male participant, Punjabi education session

The nature of caring itself can socially isolate carers, and many carers we spoke to described feeling alone due to the demanding nature of their role, and stigma from family and community members about the health conditions of their care recipients. Such feelings of isolation are well-established in the literature. Team et. al. (2007) for instance, found that many Russian female carers felt isolated both from the general community and their Russian-speaking compatriots because of their caring responsibilities, meaning they did not have substantial social networks to call upon for information or support.

The ability of family carers to carry out their responsibilities is contingent on factors such as housing, access to transport, employment, social support and family networks. As we discuss below, such factors present challenges for immigrant and refugee families who must provide care in their country of settlement with reduced social support. Underlying 'community care' as a policy is the assumption that care recipients belong to self-supporting social networks of families, friends and neighbours (Katbamna et. al. 2004). Given that immigrant and refugee carers often lack such support, evidence indicates that the policy drive to re-privatise care as 'community care' can be particularly disadvantageous to migrant women.

## STRUCTURAL CHALLENGES EXPERIENCED BY IMMIGRANT & REFUGEE CARERS

Both international and Australian literature indicate that immigrant and refugee carers face multiple, intersecting barriers in accessing social and government support services in their caring roles, and are more likely to fall within lower socioeconomic brackets (Boughtwood and Wu 2010; Gupta and Pillai 2012; Katbamna et. al. 2004; Miyawaki 2015; Spitzer et. al. 2003; Taylor 2013; Team et. al. 2007). These findings are corroborated by our stakeholder and carer consultations. Almost all stakeholders pointed to navigating the complicated (and currently changing) Australian healthcare system as a key challenge for immigrant and refugee carers. As noted above, current changes to aged, mental health and disability care and carer support services assume that individual 'consumers and carers' can exercise 'choice and control' and effectively identify and advocate for their own needs. Such self-advocacy and planning within the health system can be difficult even for fluent English-speakers who are familiar with dominant individualised cultures of service provision and biomedical approaches to health, and more so for immigrant and refugee families who may have different understandings about healing, caring, wellbeing, government intervention and service provision.

As stated by one stakeholder:

*Caregiving requires both a longitudinal perspective and holistic knowledge of the health system. However, many people do not know how to navigate the complex Australian health system, or to plan for the recipient's care with knowledge of all available services and a longer term view in mind. Because of the lack of knowledge of the health system, there is a lack of planning. For instance people may not understand that there are waiting lists for residential care, and that they need to plan and book appropriate care well before elderly relatives become too frail to live at home. Service providers can take a role in empowering clients to make these decisions.*
Stakeholder consulted for *Dealing with it myself*

Indeed, even a supposedly simple task such as calling 000 can be daunting to carers due to language barriers and the culture of constant questioning that pervades Australian health service provision:

*I have a hard time talking to the emergency people over the phone. Even though I can ask for an interpreter, their questionnaire is lengthy, I just can't cope. And they take so much time to arrive. Should I perhaps call a taxi? Because all I want to do is transport my parents to the emergency department as soon as possible.*
Female carer, Karen education session participant

Stakeholders stressed that immigrant and refugee clients require highly tailored and responsive support services, which give families sufficient face-to-face contact time with bicultural workers to develop trusting and ongoing relationships. The de-funding of ethno-specific services in favour of mainstream services presents a major challenge to creating a healthcare system which provides equitable service provision to immigrant and refugee clients. Furthermore, the complexity of care relationships within families does not always fit policy and service provider assumptions about carer-care recipient dyads.

As highlighted by stakeholders such as Carers Victoria, while an elderly spouse within a couple might be recognised (by medical staff and Centrelink) as a primary carer, in reality many elderly couples are co-dependent on each other and in turn dependent on their adult children, who take on a significant caring role because they are more confident in English and in navigating the health system.

Rahima's story (Case Study 3, page 30) is a good example of complex, intergenerational care relationships within refugee families. In this case, while the family is fairly resilient and managing their caring role up to now, they face uncertainty in planning for their parents' future care needs, due to a lack of culturally appropriate services, including respite and residential care.

Newly-arrived carers faced particular challenges during the settlement process, as highlighted in Appendix D, page 31. Many described language barriers as a key challenge in a range of caring duties – from recording and keeping medical appointments, to using public transport and understanding how the health system works. They also spoke about the complexities of life in Australia that make family caring less manageable than in their countries of origin. For instance, having to navigate long distances between suburban areas and schools, shops and workplaces; and manage eldercare, childcare, household and employment responsibilities. They described how "back home", families lived closer together; neighbours were available for support; elders participated fully in community life and were well-respected; and women had more time for household chores as schooling and employment responsibilities were less demanding, and they did not have to juggle daily tasks such as grocery shopping with children and care recipients, because vegetables were grown at home or vendors came to their door.

Importantly, we note that Australia's exclusionary visa system presents significant barriers to carers and their care recipients who do not have Australian citizenship, permanent residency or qualify for Medicare. For instance, people on temporary visas who legitimately qualified for support under the HACC program will not qualify for the NDIS, which can only be accessed by citizens, permanent residents or those holding a Protected Special Category Visa. The removal of support from care recipients will have a negative impact on immigrant and refugee caring families, creating inequitable outcomes between permanent and temporary visa holders, including compounded health problems and increased costs when people are granted permanent visas but have been excluded from timely and cost-effective early intervention measures.

One important theme emerged across sessions in all groups (Arabic, Chinese, former Yugoslavian, Hakha Chin, Indian, Karen and Punjabi) – that of 'transnational caring', or the support provided from Australia for family members who live overseas, whether this is financially through remittances; emotionally and logistically through the phone and internet; or via employees using their annual leave to fly to their countries of origin for intense periods of care. Support for transnational carers and solid understanding of the economic impacts of transnational care activities is scarce, and falls outside the scope of *Dealing with it myself*. However discussions in our education sessions indicate that costly and restrictive family reunion and aged parent visas, and the exclusion of people living with a disability from permanent residency, profoundly impact migrant families' wellbeing and economic participation. Further research is required on how such transnational caring arrangements affect families' wellbeing and workplace productivity, and how the immigration and health systems can be reformed to achieve equitable health outcomes.

## SUPPORT NEEDED FOR MULTIPLE RESPONSIBILITIES

### Carers of people living with a disability

Almost all carers and families we spoke to were highly interested in information about the service system in Australia. Carers who had already self-identified had varying levels of connection with services. Several participants described how general practitioners played a crucial role in helping them identify as carers and connecting them to services (see Case Study 4, Sara's Story, page 30). Parents caring for children living with a disability were either well-connected or at least well-aware of services available to them, although some were reluctant to use respite due to concerns about the quality of care, cultural inappropriateness or limited time to research relevant services.

For instance, one Arabic-speaking mother caring for her child with cerebral palsy stated that while she is aware of services available to her to ease her caring role (due to her professional background in nursing), she never uses respite services because her son becomes agitated around strangers or unfamiliar environments. Another mother looking after her adult son living with an intellectual disability recounted how she spent a long time becoming comfortable with the idea of a 'stranger' (paid carer support worker) helping to care for her son. Although she was born in New Zealand and fluent in English, culturally she identified closely with her Arabic-speaking parents, and it has taken many years for her to research and find services with which she and her son are comfortable. She stated that waiting periods for culturally-tailored services are too long, and she expressed concern about the current policy context in which families such as hers are finding it increasingly expensive to provide appropriate care to family members. Another Arabic-speaking carer suggested that if TAFE or community service organisations ran aged and disability care courses in multiple languages (without high-levels of English proficiency being a pre-requisite), this would result in less people missing out on multicultural respite or having to wait for excessive periods of time for relevant respite workers to become available.

One Indian mother of an adult son living with autism, who was also familiar with the service system and worked as a care coordinator herself, commented that she never uses out-of-home respite services despite feeling confident in accessing them, due to negative experiences:

*We have tried a few respite places, Department of Human Services and Family respite places, they were almost like a prison really. We go there and he [my son] just stays... he can't get out, all the doors are locked, and we can't take him out. I thought maybe I would get him used to being out of home, if I had to go somewhere, I could leave him there, but he's never been comfortable – not eating, not sleeping, even when we left him over night, he would not sleep, and the next day I had to...they would not clean him properly...and it hasn't worked out for me. I'm not sure about the others but it hasn't worked out for me. I know it's respite for me, but it should be a good service for my son as well. He should be happy there.*

Indian female carer, interviewed for *Dealing with it myself*

## Carers of the elderly & hidden carers

Carers for the elderly and hidden carers were not always aware that services are available in Australia, but they were keen to learn more. During most education sessions, participants were unaware of the suite of support services available for care recipients and carers, including respite services; taxi cards, companion cards or the Victorian Carer Card; and aged care assessments and home care packages. Evaluation forms from all of our 49 community education sessions indicate that participants showed great interest in learning about services that could help them now or in the future. Some participants expressed hesitance about seeking services, but largely because of barriers to access:

*All the forms [for accessing services] are on internet and in English. We don't know how to use computers and fill in forms.*

Male participant, Karen education session

*I would like to access all these services, now that you have told. But who is going to fill in all these forms for me? I cannot use the internet or write much in English. I need help with filling in forms all the time but there is not much help out here [in Bendigo]. Only information doesn't help me.*

Female participant,Karen education session

The fact that so many participants of our sessions appreciated learning about services should dispel the stereotype of immigrant and refugee families facing 'cultural' barriers in accessing services because they prefer to 'look after their own' (FECCA 2015). Rather, barriers to access are predominantly structural, with families having little time to research services, being excluded due to language, geographic location or lack of transport or funds, and experiencing poor quality or culturally inappropriate support which can intensify rather than ease familial understandings of the caring role and who should be responsible. Such structural barriers are illustrated by the following story from one of our interview participants:

*I tried to get some services in only once, but there was so much resistance from the extended family. My mother-in-law had become quite unstable on her feet and needed help showering. But the services that we got were badly targeted.*

*As an Indian woman, the first thing she wants to do in the morning is shower and do her morning prayers. If she doesn't pray, she can't eat, so there's a cascade effect. When you have a home nurse visiting at 11:30am, how's that going to work? She would drag herself down the stairs and put herself in the shower, and do everything by herself in an un-safe way. By the time the nurse had arrived, everything had been done... A few times I'd ring them [services] and ask if she could be the first one who the home nurse visits. But somehow it was never able to be done. So we just got rid of the service... I'm pretty sure that if I attempt again to get outside services in, there will be world war three with the extended family. Because [my husband's family] don't really see that she needs anything, although my husband and myself really feel that she does.*

Female carer interviewed for *Dealing with it myself*

It is important to support immigrant and refugee carers because they face additional, intersecting structural barriers in accessing appropriate health care. While it is vital that support services themselves are tailored to meet the needs of individual carers and caring families, from a health promotion perspective it is equally important that community education and information about the impacts and challenges of caring are directed more broadly, in order to increase understanding and support for carers in the general community, including care recipients, colleagues and other family members and friends.

Immigrant and refugee carers and care recipients in Australia often have less access to both informal and formal supports to mitigate the impacts of the caring role. This is due to intersecting structural barriers including:

- language barriers;

- culturally inappropriate service provision;

- social and family isolation;

- restrictive, confusing and ever-changing visa entitlements;

- transport issues and costs;

- a changing and complex health system; and

- discrimination and racism when seeking employment and attempting to access support services (see FECCA 2015 and Taylor 2013).

Public health and health promotion workers have long recognised that health services in western countries are developed on the basis of the needs of the majority, English-speaking population. In order for immigrant and refugee health outcomes to improve, it is vital that health services work towards removing the systemic barriers service access listed above.

Carers have overwhelmingly told us that they would use services if:

a) information about such services is delivered to them in a culturally and linguistically appropriate manner (the main aim of *Dealing with it myself*); and

b) services themselves are trustworthy, culturally and linguistically appropriate and of high quality.

Timely, holistic support for immigrant and refugee caring families will greatly improve the health and wellbeing of carers and care recipients and reduce financial burden on the Australian healthcare system via early intervention. Such support can be achieved by funding high quality multicultural services.

While we acknowledge the need for economies of scale in delivering services, we also note that generalised services which do not address intersecting forms of disadvantage are much less effective than services which are tailored for and targeted to immigrant and refugee families. Such tailoring must recognise the diversity and gender dynamics within cultural groups to be truly effective.

## RECOMMENDATIONS

We recommend the following actions to improve the physical health, psychological wellbeing and social connectedness of immigrant and refugee carers:

- **Strengthening intersectional policy analysis:**
  Embedding a gendered, intersectional framework to examine the impact of specific policy approaches on immigrant and refugee women and families. Analysis and evaluation of proposed healthcare policy and service delivery options should address the disproportionate amount of unpaid caring currently undertaken by women in Australia, as well as the multiple forms of disadvantage and barriers to accessing services experienced by immigrant and refugee families (including racism, discrimination, ethnocentrism in service delivery, and language barriers).

- **Co-designing future support services with immigrant and refugee carers:**
  Engaging immigrant and refugee carers in the co-design of service options through active outreach and consultation by bicultural staff.

- **Removing residency restrictions:**
  Making support services available to carers and care recipients on all visa categories in Australia to avoid a multi-tiered system in which certain groups of residents and citizens have access to more support than others, and to recognise the immense economic contribution of all carers in Australia, regardless of their residency or citizenship status.

- **Ensuring high quality and culturally appropriate service delivery by:**

  - increasing funding for multicultural and ethno-specific organisations with expertise in advocacy, case management, respite and residential care services, with eligibility determined on the needs of carers as well care recipients;

  - providing sustainable funding for healthcare and social services to offer comprehensive, ongoing, in-person support and case management to immigrant and refugee families accessing their service, as technology-based modes of service delivery exclude many families from accessing timely early intervention services;

  - ensuring immigrant and refugee clients do not pay for interpreting, translating or necessary service-coordination and advocacy support out of their packages under consumer-directed care models, as this limits their access to support services relative to non-migrant families; and

  - ensuring affordable access to childcare as well as multicultural respite, addressing women's family caring responsibilities holistically.

- **Delivering cross-cultural training:**
  Training social welfare and health care staff in gendered cross-cultural awareness, identifying hidden carers and supporting immigrant and refugee clients. Such training should target key organisations carers interact with, such as aged care, mental health and disability services; Centrelink; My Aged Care Regional Assessment Services; medical centres; hospitals; and the proposed regional hubs of the national integrated carer service.

- **Facilitating community health education:**
  Delivering bilingual health education sessions about the importance of supporting carers and identifying hidden carers in the community. This can be achieved by replicating the Dealing with it myself model with other communities.

- **Improving workplace support:**
  Effectively facilitating family-friendly workplace policies in sectors which have a high proportion of immigrant and refugee employees – including aged care, child care and hospitality.

- **Developing culturally-responsive peer support:**
  Sustainably resourcing peer support-like activities co-designed with immigrant and refugee caring families. Groups require long-term ongoing support for facilitation, respite, transport, and options to involve care recipients. Such support is required beyond 'pilot programs' through which groups are established but then left unsupported.

- **Conducting participatory action research on:**

  - the experiences of carers from multicultural communities, ensuring adequate resources to reach the most isolated carers (i.e. funding for bicultural workers, and reaching regional and rural carers);

  - the ageing preferences and service needs of immigrant and refugee communities, to address assumptions about preferences for 'ageing at home' and to generate high quality data on effective service delivery models;

  - the health, wellbeing and economic impacts of 'transnational caring' (defined as providing support and care across distance and national borders); and the impact of immigration policy, changing rules to contributory, aged parent, carers and family reunion visas, and welfare policies that penalise people for travelling outside of Australia for extended periods of time; and

  - the association and causality between casual and part-time employment on the one hand and caring responsibilities on the other.

# APPENDIX

## APPENDIX A:

### PROJECT ADVISORY GROUP MEMBERS & REPRESENTED ORGANISATIONS

Gabriel Aleksandrs (formerly Ailsa McPherson): Carers Victoria

Claire Emmanuel: Alzheimer's Australia Victoria

Angie Karabatsas: Merri Health/CarerLinks North

Anand Shome: IndianCare

Fiona York (former): Ethnic Communities Council of Victoria

## APPENDIX B:

### LIST OF STAKEHOLDERS CONSULTED

Action for Disability within Ethnic Communities Inc.

Alzheimer's Australia Victoria

Carers Victoria

Catholic Care (Footscray)

Dianne Iounnou (advocate for mental health carers from immigrant and refugee backgrounds)

Ethnic Communities' Council of Victoria (ECCV)

Federation of Ethnic Communities Councils of Australia (FECCA)

IndianCare

Merri Health/CarerLinks North

National Ageing Research Institute (NARI)

Southern Migrant Resource Centre (SMRC)

Tandem Carers

Victorian Arabic Social Services Inc. (VASS Inc.)

Women's Centre for Health Matters

# APPENDIX C: *DEALING WITH IT MYSELF* CASE STUDIES

## CASE STUDY 1: JOANNA'S STORY

Joanna arrived in Australia from a Thai refugee camp with her family a few years ago. Recently, she quit her part-time job to care for her elderly mother after a stroke. Her mother is now paralysed and cannot move her arms or legs. Joanna does everything for her, including changing her adult diapers, cooking, feeding and showering, and even helping her with itches and other skin discomforts when she cannot reach them.

As Joanna and her mother felt more comfortable seeking advice from the community nurse, the nurse provided them with a special bed which can be moved up and down with ease.

At first, Joanna felt guilty about using this equipment because her mother raised Joanna and her siblings "with her own hands", without any other help.

*"I thought to myself, 'She is my mother and she did everything for me when I was little, and I have to take care of her to thank her back'. So I did everything using only my own hands. But after a few months, my knees and back started to hurt because I didn't use the equipment to move her. I realised that I wasn't taking care of myself. Sometimes even now I don't want to use that equipment, but if I don't, I feel tired and flat. It's true that you have to take care of yourself before taking care of others, and you have to use the appropriate things that will make it better."*

## CASE STUDY 2: SUE'S STORY

Sue arrived in Australia from China 23 years ago with her family. She lives with her parents and her two daughters, and works full-time. Her parents are elderly, and although they do not have high-care requirements, she has provided them with significant financial and emotional support over several years.

Despite providing her parents with support and housing, her parents have always financially supported her brother rather than Sue and her family. Sue thinks it is typical for Chinese parents to invest in sons and grandsons rather than daughters, because male descendants carry the family name. However, she feels hurt that her parents overlook her needs, and their lack of support has caused much strain and resentment with her former husband, who questioned the fairness of her parents' actions. Sadly, the conflict with her husband over providing most of the care for her parents while they supported her brother eventually resulted in the breakdown of her marriage.

Without her former husband's financial support, she now has to support five people (her parents, her two daughters and herself) on her relatively low income as a childcare worker. She devotes every Saturday to her parents, taking them out for shopping and lunch at their favourite yum cha restaurant. The weekly outing is not necessarily about food, but rather about keeping her parents happy and maintaining their emotional wellbeing. She is also responsible for all the housework, which she completes on Sunday. This leaves her with no time for looking after herself, or to pursue any hobbies or enjoyable activities.

Even before her husband divorced her, he never helped with housework due to his resentment, and she shouldered most of the household burden. Although she actively and deeply cares for her parents, she feels upset about her parents' lack of support for herself. She thinks that if her parents had provided her and her former husband with just a little financial support, it would have greatly lightened the strain in their relationship.

## CASE STUDY 3: RAHIMA'S STORY

Rahima arrived in Australia 21 years ago from the former Yugoslavia (now Bosnia). Her elderly parents moved to Australia a few years later. Her father suffers from brain damage due to a wound he received when they were attacked during the war.

As Rahima put it, "*We were in the wrong place at the wrong time, because Muslims in Bosnia were being targeted*". Now they are in Australia, her mother is officially her father's primary carer, but Rahima, her sister, their husbands and adult children do a lot as secondary carers because neither of her parents can speak English, and her mother is elderly herself.

As an extended family they run a small business (a shop), and so they are able to divide the caring tasks and medical appointments amongst themselves.

However, the caring role has caused significant financial strain. Rahima described herself as working a "*full-time and a half week*", because "*you can never switch off when running your own business*". She adds about the families' caring responsibilities in general, "*It's stressful, but we're managing*". While her family are quite comfortable using medical services for the time being, they do not use respite services as most are only offered in English.

Rahima and her family are worried about the prospect of having to use respite services or long-term residential care as her parents reach the age when they can no longer be cared for at home, as they have not found any services in Bosnian.

## CASE STUDY 4: SARA'S STORY

Sara is an Arabic-speaking mother caring for her ten year old son. Between the ages of two and four, Sara took her son to several doctors, but they were never able to diagnose him correctly, and repeatedly advised her to "*give him more time*".

Finally, he was diagnosed with autism at the age of six. This was a difficult time for Sara, as she knew there is no cure for autism, but she was relieved that her son had received a diagnosis.

From this point her family doctor was extremely helpful in connecting her with services, both for her son (speech therapy and psychology) and for Sara herself, helping her complete forms to help access Centrelink payments and various carer support services.

This support has given Sara the confidence to stay positive and communicate closely with her son's teachers about his progress. "*In order to continue my hard role, I give myself a break and do special things from time-to-time*".

## APPENDIX D: STORIES FROM NEWLY ARRIVED KAREN CARERS

*"My mother and father have dementia and sometimes it can be difficult. If we go to a medical appointment and have to wait a long time, they want to go back home. Every time we go, we have to wait more than 30 minutes, but they cannot sit that long because they are very old. I have to take them to all their appointments and find it very hard to get them into the car with their wheelchairs. They have started acting like children.*

*At home they have to wear an incontinence pad. Every time they go to the toilet, they take the toilet roll and put it into the pad. Especially my mum, she does that all the time. When I ask her why, she says she is keeping it safe for next time. Sometimes she puts the roll in the toilet and it becomes blocked. Now we always hide the toilet rolls from her.*

*When it is cold they do not want to go to their appointments and want to hold a hot water bottle all the time. If we do not boil the water for my mum, she will just try to do it by herself. I sometimes feel upset at them. We do not want her to burn herself. It's very hard for me to care for my family and children at the same time as my parents. But I do not want to put them into an aged care facility. If we had a Karen aged care facility, then maybe I would consider putting my parents there."*

*"For me, I am caring for my husband but I know nothing as I am just new to this country and my case worker is doing everything for me.*

*My husband has very complicated health issues. We have been here for four months now and he has been to hospital many times already. He had a colon rupture and an operation. Up until now his kidney and his bladder are not working well and we have to see the specialist not only in the Werribee Mercy Hospital but also at Footscray Hospital. It seems like he has lost his mind sometimes, and even when we arrive at our bus stop, he doesn't know which way to go back home. Maybe we are new and we are losing our way all the time."*

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