

**AIPCA**

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**Australian Institute  
for Primary Care & Ageing**

**Aged care for  
older survivors of  
genocide and  
mass trauma**

*Developing  
an aged care  
training model*

**November 2010**

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## Executive Summary

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The Caring for Older Survivors of Genocide and Mass Trauma project was initiated by Jewish Care Inc. Victoria in 2006. That study explicitly set out to address an identified gap in knowledge about aged care for older survivors and training aged care workers for providing that care. The main aim was to develop an evidence-based model of staff training for carers of older survivors in aged care. The project focused on the care of two groups of older survivors who endured the trauma and losses of genocide many decades ago—Holocaust survivors and older Cambodian people.

Chapter 1 of this report includes a description of the project background, the research questions, and a review of the literature. The literature indicates that older survivors of genocide and mass trauma (older survivors) are a distinct client group in aged care and that they are at risk of exposure to reminders of prior trauma in aged care settings (Brodsky, Sharon, King, Be'er, & Shnoor, 2010). The need to train aged care workers for working with older survivors in Australia is documented in the literature (Gifford, Atwell, & Correa-Velez, 2007; NSW Refugee Health Service, 2006).

Chapter 2 covers the project methodology. Data collection was conducted in 2008–2009. Based on Australian Bureau of Statistics (ABS) 2006 Census data, five Local Government Areas in Melbourne were selected for this study: Kingston, Greater Dandenong, Port Phillip, Glen Eira and Whitehorse. The project used qualitative research methods to investigate the experiences of older survivors in using aged care services, and the experiences of aged care workers in providing this care.

Community consultations were held with key representatives from 16 generalist, multicultural and ethno-specific providers of aged care and other support services. Ten focus groups were held with 90 aged care workers from a range of organisations that provide community and residential aged care services. In-depth interviews were conducted with 22 older survivors and eight family carers about their experiences of using community and residential aged care services. Interviews with the older survivors helped shed some light on the impact of past traumatic experiences on their current experiences of aged care services. Fourteen in-depth interviews were conducted with aged care and welfare professionals who had experienced working closely with the two older survivor groups. These interviews enabled researchers to obtain ‘thick’ descriptions of themes that emerged from the other data collections.

This study explicitly set out to address an identified gap in knowledge about aged care for older survivors and training aged care workers for providing that care. The key construct that emerged from the research was ‘trauma-sensitive, person-centred care’ (TS\_PCC). The construct was generated by applying the principles of person-centred care and knowledge about trauma and ageing to the themes that emerged from the qualitative data analysis. The research identified the knowledge, attitudes and skills that underpin this construct. This information forms the basis for the training model outlined in Chapter 5. The expected immediate outcomes of the training are changes in participants’ level knowledge and the formation of trauma-sensitive, person-centred attitudes. The expected intermediate outcome is improved aged care practice.

## Chapter 1: About the project

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### Background

The ‘Caring for Older Survivors of Genocide and Mass Trauma’ project advisory group was established in 2006 by Jewish Care Inc. and La Trobe University researchers in recognition of the need to prepare aged care staff for working with older survivors of genocide and mass trauma—referred to as ‘older survivors’ in this report. Jewish Care Inc. had identified the need to develop evidence-based training for aged care workers to improve the way they interacted with Holocaust survivor clients in both residential and community aged care. It was considered vital that the training program be flexible enough to be delivered to all levels of aged care personnel (including managers, team leaders, allied health personal, and direct care workers).

The project focused on two groups of older survivors who endured the trauma and losses of genocide many decades ago and subsequently resettled in Australia—Jewish survivors of the Holocaust and survivors of the Cambodian genocide. The vast majority of Holocaust survivors living in Australia today are aged in their 80s and 90s. The child survivors are mostly aged in their 70s. Most adult survivors of the Cambodian genocide who live in Australia today are aged over 60, with some in their 70s and 80s. These two groups of older survivors underwent periods of resettlement, social adjustment and rebuilding their lives decades ago. The literature suggests that some older survivors are vulnerable compared with other older people because they may be simultaneously facing age-related life transitions, such as declining health and widowhood, and worsening of past traumatic memories. The literature also suggests that older survivors may experience aged care (in particular, residential care) as a recapitulation of earlier traumatic experiences.

A small-scale scoping study supported by a grant from La Trobe University’s Faculty of Health Sciences was conducted in 2006. It examined issues relating to the provision of aged care services for Holocaust survivors and survivors of the Cambodian genocide. Consultations held with representatives from 14 mainstream and ethno-specific organisations found that aged care managers were concerned about the capacity of aged care workers to provide compassionate, sensitive and individualised care for older survivors. Those who participated in the consultations also perceived a general lack of knowledge among aged care workers about events such as the Holocaust and the Cambodian genocide, and the long-term impacts of these events on older aged care clients. These findings, combined with a preliminary review of the literature, led the project advisory group to conclude that there is a need to:

1. Prepare aged care workers for working with clients from these backgrounds
2. Develop evidence-based staff training on caring for older survivors in the aged care sector.

The project was successful in attracting funding for the research to be conducted in 2008–09, from the ANZ J.O. and J.R. Wicking Research Fund, with additional support from Aged Care Branch of the Victorian Department of Health and Jewish Care Inc. (Victoria). The aims of the project were:

1. To investigate older survivors’ experiences of aged care and aged care workers’ experiences of providing this care.
2. To develop an evidence-based training model intended to enhance aged care workers’ competency for working with older survivors in the community and in residential aged care.

The research was conducted by the Lincoln Centre for Research on Ageing in the Australian Institute for Primary Care & Ageing (AIPCA). The study adopted qualitative research methodology.

### **Research questions**

1. How do older survivors of genocide and mass trauma and family carers experience community and residential aged care services?
2. How do aged care workers experience providing this care?
3. How do older survivor clients' prior traumatic experiences influence the provision of aged care services?
4. How is optimum care for older survivors provided?

### **Literature review**

#### **Definitions and demography**

Since World War II, Australia has been a place of resettlement for successive waves of migrants from war-torn countries including refugees from European countries, who arrived in the 1950s and 1960s, and immigrant and refugee groups that arrived in the 1970s and 1980s from conflict areas such as Lebanon, Central and South America, Cambodia, Laos and Vietnam. Prior to their eventual resettlement in Australia, many of these migrants endured traumatic experiences such as persecution, torture, separation from family, organised mass violence and killing, displacement and multiple relocations.

*Genocide* is a term that was created during the Holocaust. Genocide was declared an international crime in the 1948 United Nations Convention on the Prevention and Punishment of the Crime of Genocide. The Convention defines genocide as any of the following acts committed with the intent to destroy, in whole or in part, a national, ethnical, racial or religious group. The specific 'intent to destroy' particular groups is unique to genocide. A closely related category of international law, *crimes against humanity*, is defined as widespread or systematic attacks against civilians. *Mass trauma* is a more general term than genocide and refers to the traumatisation of a population as a result of war and massive killing in their country. In contrast to the concept of genocide, the notion of mass trauma does not include targeting on the grounds of religion or race.

The term *Holocaust* refers to the extermination of six million Jews during the Nazi era (1933–45). Nazi policy was to systematically and meticulously erase the Jewish race. Initially, Jews had their homes taken away, property confiscated, businesses destroyed and families separated. Nazis treated Jews like criminals and expected total submission. Nazi terror centred on the ghettos where Jews were forced to live, segregated from the rest of society. The ghetto was a holding place for people before they were systematically deported to concentration camps and extermination sites. Holocaust experiences included forced slave labour in mines, factories, farms and battle zones, pogroms in areas occupied by the Nazis and their collaborators, death camps in which degrading living conditions were coupled with technologically sophisticated, organised massacres; concealment in buildings, sewers, and forests; fighting as partisans; and passing as Christians, with false documents. A Holocaust survivor is defined as any Jew who lived in a country under a Nazi or Nazi collaborator regime or under Nazi occupation, as well as any Jew who fled owing to a Nazi regime or occupation (Shmotkin, Blumstein, & Modan, 2003).

In the 1930s, approximately 8,000 European Jewish refugees migrated to Australia to escape persecution by the Nazi regime. After World War II, about 35,000 survivors of the Holocaust arrived in Australia and settled mainly in Melbourne and Sydney. Australia has the highest number of Holocaust survivors per capita outside Israel (Rutland, 2005).

The *Cambodian Genocide* (1975–1978) was an attempt by Khmer Rouge leader Pol Pot to reconstruct Cambodia into a communist peasant farming society. The population was forced to work as labourers in one huge federation of collective farms. At short notice and under threat of death, the inhabitants of towns and cities were forced to leave their homes. People who refused to leave were killed; as were those who did not leave fast enough, and those who refused to obey orders. All political and civil rights were abolished. Children were taken from their parents and placed in separate forced labour camps. Factories, schools, hospitals and universities were shut down. Lawyers, doctors, teachers, engineers, scientists and professional people in any field (including the army) were murdered, together with their extended families. Religion was banned, all leading Buddhist monks were killed and almost all temples were destroyed. Music and radios were also banned. People who escaped murder became unpaid labourers, working on minimum rations and for impossibly long hours. They slept and ate in uncomfortable communes deliberately situated as far as possible from their old homes. Personal relationships were discouraged; so were expressions of affection. Also targeted were minority groups including ethnic Chinese, Vietnamese and Thai, and also Cambodians with Chinese, Vietnamese or Thai ancestry. An estimated two million Cambodians died from starvation, overwork and by execution.

Between April 1975 and June 1986, the number of Cambodians who came to Australia under the Refugee and Special Humanitarian Program was 12,813; approximately 3,500 re settled in Australia under the family migration stream in the 1990s. The number of Cambodian-born people in Victoria in 2001 was 9,022 (Australian Bureau of Statistics, 2006).

### **Long-term impacts of trauma**

Clinical and empirical research shows that the psychological effects of acts of organised and mass violence have a predictable impact on individuals. This has been referred to in the literature as a ‘trauma reaction’ (Kaplan, 1998). The Victorian Foundation for Survivors of Torture (VFST) ‘trauma reaction’ model outlines four components that include: anxiety, helplessness and perceived lack of control; grief and depression; shattered assumptions about human existence; guilt and shame.

There is a vast literature on the long-term effects of extreme trauma on the mental health of people from refugee backgrounds. Much of this research focuses on long-term post-traumatic symptomology, post-traumatic stress disorder (PTSD) and diagnosis. The reported psychological impacts of extreme trauma include severe loneliness and isolation, suicidal behaviour, panic disorder (Bower, 1994; Carlson & Rosser-Hogan, 1993; Collins, Burazeri, Gofin, & Kark, 2004; Uehara, Morelli, & Abe-Kim, 2001), repressed expression of emotions and problems, and unwillingness or inability to disclose traumatic personal experiences (Ben-Zur & Zimmerman, 2005).

Some of this body of research has examined the lives of survivors of trauma in their ageing years. The literature indicates that severe traumatisation can persist for many years after the actual trauma took place (Amir & Lev-Wiesel, 2003; Boehnlein, 1987; Boehnlein, Kinzie, Ben, & Fleck, 1985; Landau & Litwin, 2000; Sadavoy, 1997; Trappler, Braunstein, Moskowitz, & Friedman, 2002). Among Holocaust survivors, various rates for the prevalence of PTSD are quoted, ranging between 39% and 65%; sleep disturbance is reported to be the most common post-trauma symptom among Holocaust survivors (Kellermann, 2010).

Australian research has found that older people from Cambodian and Vietnamese backgrounds have health and wellbeing needs that are distinct from those of migrants who did not experience extreme traumatic stress (H. Joffe, Joffe, & Brodaty, 1996; Steele, Silove, Phan, & Bauman, 2002; Thomas, 1999). Research with Holocaust survivors living in Australia has found that while their social and daily functioning was normal 55 years after the end of World War II, they functioned worse on a range of psychological measures than two control groups of older Jewish people who were not in Europe during the war (C. Joffe, Brodaty, Luscombe, & Ehrlich, 2003). Holocaust survivors in Israel report higher rates of depression, sleep disorders, feelings of loneliness, negative attitudes towards their own health, problems associated with mobility outside the home, lower social activity, and require higher intensity of home care than other older people living in Israel (Brodsky, 2005; Brodsky, et al., 2010).

Other issues for older survivors of genocide and mass trauma raised in the literature include the likely possibility of premature ageing as a late effect of the experience of genocide, especially if this occurred during puberty (Ohry & Shasha, 2006); the inability to ever fully disengage from the representations of loved ones who were killed during the period of genocide or mass trauma (Bar-Tur & Levy-Shiff, 2000); and food-related issues that derive from older survivors' experiences of starvation Sinder, Wellman, and Stier (2004) found that these issues persist for Holocaust survivors more than 60 years after the Holocaust. Five themes emerged from their research: difficulty throwing food away, even when spoiled; storing excess food; craving certain food(s); difficulty standing in line for food; and experiencing anxiety when food is not readily available.

Clinical evidence suggests that older survivors with dementia often experience the intrusion of terrifying and painful memories of earlier trauma upon their current reality. Care providers have suggested that for older survivors with dementia reliving the painful past may be exacerbated by aspects of their current environment—particularly in residential aged care facilities—resulting in delusions and paranoia. David and Pelly (2003) suggested that having been stripped of recent memory, these older survivors may revert to behaviours that were essential to survival during the period of traumatising.

### **Trauma and ageing**

Two contrasting perspectives on the ways in which traumatic life experiences affect the normative process of ageing are identified in the gerontology literature: increased vulnerability versus increased resilience (Suedfeld, et al., 2005). Much of the research on older survivors of extreme traumatising, which was derived from clinical studies on Holocaust survivors and combat veterans, supports the vulnerability perspective. This perspective proposes that life events such as retirement, children leaving home, deteriorating health and death of a loved one can trigger latent post-traumatic stress symptoms in a manner that will make it difficult to adapt to the development phases of ageing (Danieli, 1997). The research has suggested that during ageing, survivors of trauma are at risk of a worsening or sudden onset of post-traumatic symptomatology, even after decades of adequate coping. This pattern of symptomatology applies to those who experienced trauma as adults, as well as, those who experienced it as children (Aarts & Op den Velde, 1996).

Some researchers have suggested that too much emphasis has been placed on the psychological effects of trauma, and not enough on health-promoting factors such as growth, adaptability and resourcefulness. Bonanno, Rennie, and Dekel (2005) stated that resilience is the most commonly observed outcome following a traumatic event. The resilience perspective focuses on how older survivors have managed to put their lives back together and achieve emotional stability, familial love,

inner satisfaction and happiness. Lomranz (2000) spoke of the 'skewed image of the Holocaust survivor'.

Shmotkin (2003) suggested that the sequelae of extreme trauma should be understood in joint terms of vulnerability and resilience, emphasising variability between individuals rather than uniformity in coping potentials. Some researchers have suggested that individuals who previously experienced traumatic losses often regard age-related losses as secondary, enabling them to better cope with those losses, and in some cases, to turn them into opportunities for further development. Others have proposed that older survivors function on two levels. In the external, functional world, many are well-adapted; however, in the inner world, they continue to be emotionally engaged with the deceased and to experience increased pain (Kellermann, 2010).

### **The impact of prior trauma on older survivors' experiences of aged care services**

As older survivors become more dependent on others due to declining physical health and/or cognitive capacity, they may come into contact with aged care services. The point at which this contact occurs is influenced by the individual and their family's cultural perspective on filial responsibility, the availability of family members to provide care, attitudes towards government services in general, and ability to access information about aged care services. The evidence suggests there are high levels of unmet need for community care and social support services among older refugees (Gifford, et al., 2007; NSW Refugee Health Service, 2006).

Literature on older survivors' experiences of aged care services is sparse. Some of the literature suggests that events such as relocation to residential care and hospitalisation are 'gateways to psychopathology' (Lomranz, 2005) p. 257) due their potential to induce feelings of helplessness and reactivate traumatic memories. Holocaust survivors have been reported to find entry into residential care to be profoundly disturbing (Hirschfeld, 1977; Zilberfein & Eskin, 1992). Adams, Mann, Prigal, Fein, and Souders (1994) found that on entry to nursing homes, some Holocaust survivors exhibit significant fear, resistance, and paranoia when faced with moderate to total dependence on others for their nursing care. Other studies found have less evidence of this effect. Shour (1990) found that Holocaust survivors living in a nursing home in Canada were by and large similar in their behaviour and psychosocial and physical needs to the other residents; however, they tended to use a greater number of medications and to access fewer medical services and they were more likely to be described as being aggressive than other residents. Letzter-Pouw and Werner (2003) found no differences between the Holocaust survivors and a comparison group on their willingness to enter a nursing home.

### **Practice and training issues in aged care for older survivors**

While aged care workers may be the second most likely professional group to have direct contact with older survivors (after health professionals), little has been written about their experiences of caring for older survivors. Much of the published literature on this topic comes from the social work and nursing sectors. It shows that nurses and other staff working in aged care can often describe older survivor clients as 'difficult' and that it is vital for staff to develop understanding and empathy with the individual's earlier trauma (Adams, Mann, Prigal, Fein, & Souders, 1994; Ehrlich, 2004; Levine, 2001).

Shour (1990) found that Holocaust survivors in a Canadian nursing home were more likely than other residents to be described as being aggressive. Language appeared to contribute to some of the aggressive behaviour attributed to survivors. Leonhard (2003) examined the experiences of 18 nurses in Israel who worked with elderly Holocaust survivors in the community, in homes for the aged, and in hospitals. The nurses described caring for these people as being especially hard, because it takes an enormous amount of patience, time, understanding, and attentiveness.

Health care professionals in Australia are unlikely to recognise the needs of older people from refugee-like backgrounds as distinct from the needs of other migrant groups, and unlikely to have the knowledge, training, skill, or personal assurance to deal with the effects of mass trauma (H. Joffe, et al., 1996). Australian resources for professionals who provide services for refugees are available (Australian Centre for Posttraumatic Mental Health, 2007; Victorian Foundation for Survivors of Torture, 2007). The quality of the relationship with a survivor of trauma is the foundation upon which the effectiveness of any intervention rests. Good working relationships between workers (counsellors, teachers, counsellors, health professionals, and immigration officers) and trauma survivors focus on enhancing predictability and control, promoting trust, and reducing fear and shame (Kaplan, 1998). These resources do not focus on the specific issues faced by older survivors or on the provision of aged care services.

Efforts in Australia and abroad to teach aged care workers about caring for older survivors have emphasised: awareness and knowledge about historical events; trauma experiences; trauma responses; normal day-to-day activities or situations in aged care that may provoke adverse physical, emotional, or behavioural reaction; and strategies for building trust and offering personal control (Adams, et al., 1994; David & Pelly, 2003; Ehrlich, 2004; Levine, 2001; Pillars, Grossman, & Symonds, 2005). Aged care practitioners have argued that health and aged care staff who work with older survivors need contextual and practical information on how to handle challenging situations (David & Pelly, 2003). They emphasise building trust and enhancing personal control (Adams, et al., 1994) and avoidance of applying the post-traumatic stress label to symptoms that may be due to other physical or mental causes (Carstairs, 2004). (Abrams, 2000) argued that training is particularly important for direct-care workers who provide care for older survivors, such as nursing assistants in residential care and home help workers in the community. The Holocaust Resource Project at Baycrest Centre in Canada compiled a resource package to educate and sensitise direct service providers working with Holocaust survivors and their families (David & Pelly, 2003). It documents the many normal day-to-day activities or situations that may provoke adverse physical, emotional or behavioural reaction among Holocaust survivors, especially in institutional settings.

## **Conclusion**

The literature on caring for older survivors in aged care is sparse. It suggests that older survivors may experience institutional care as a recurrence of earlier disruptions in their lives. The literature also points to the challenging situations that care professionals can face with this client group in institutional settings; however, there is a lack of research on older survivors' experiences of community care services. Few studies have examined the older survivors' perspectives of residential and community aged care services. Efforts to teach health and aged care workers about caring for older survivors emphasise the importance of understanding every client within the context of their own life history and of building trust and offering personal control.

## Chapter 2: Methodology

The study used the social constructivist perspective of qualitative research advocated by (Charmaz, 2006), which emphasises diversity of local worlds, multiple realities, and the complexities of particular worlds, views and actions. Qualitative data were gathered about older survivors in aged care from the differing perspectives of the older survivors, family carers and aged care workers. In recent years, research has provided increasing evidence to support the assumption that historical events such as wars can and do have both a profound and a sustained impact on the ways in which individuals respond to, and cope with, the numerous and often cumulative challenges that arise during the final decades of life. According to Kenyon, Clark and de Vries (2001), gerontologists have turned to narrative approaches in attempts to understand ageing from the inside. Life stories highlight the context within which individuals develop and through which experiences are understood (de Vries & Suedfeld, 2005).

### Study groups and study areas

This study focuses on two groups of older genocide survivors living in Melbourne—Jewish survivors of the Holocaust and older Cambodian people. The project was conducted in five Local Government Areas (LGAs) in Melbourne identified using 2006 ABS Census data (Australian Bureau of Statistics, 2006) as the main places where members of the Jewish and Cambodian communities reside. Based on this information, the following LGAs were selected: Glen Eira; Port Phillip; Greater Dandenong; Kingston; and Whitehorse.

**Table 1: Cambodian-born residents living in target LGAs in Victoria by age group**

Local Government Area (LGA)	Number of Cambodian-born people (All ages)	Number of Cambodian people aged 65+	% of total Cambodian pop'n aged 65+
Greater Dandenong	4,679	288	6.2
Kingston	1,005	72	7.2
Whitehorse	500	57	11.4
Other LGAs	3,606	224	6.2
<b>Total Cambodian-born pop'n in Victoria</b>	<b>9,790</b>	<b>641</b>	<b>7.0</b>

**Table 2: Jewish residents living in target LGAs in Victoria by age group**

	Number of Jewish people (All ages)	Number of Jewish people aged 65+	% of total Jewish pop'n aged 65+
Glen Eira (C)	22,060	3880	18.0
Port Phillip (C)	3,921	1082	28.0
Other LGAs	14,222	2822	20.0
<b>Total Jewish pop'n in Victoria</b>	<b>42,015</b>	<b>8130</b>	<b>19.4</b>

## **Data collections**

Data collection began in early 2008 and was completed at the end of 2009.

## **Community consultations**

Community consultations were held in the first half of 2008 with representatives from 16 care and support organisations including migrant resource centres, peak bodies and aged care service providers (generalist and ethno-specific). The list of organisations involved in the community consultations is shown in Appendix 1. The main aim of the community consultations was to develop rapport with a network of contact people to assist the researchers in gaining access to older survivor clients, family carers and aged care sites.

## **In-depth interviews with key experts**

Interviews were conducted with 14 key experts working with older survivors in the Jewish and Cambodian communities. These experts came from health, aged care and counselling backgrounds. Two allied health professionals, three case managers, three social workers, four activities coordinators, a Rabbi working in a Jewish residential care facility and a Buddhist monk were interviewed. Some interviewees spoke from the dual perspectives of being both care providers and survivors themselves (either child survivors or children of survivors).

## **Theme list**

A semi-structured set of questions was developed to elicit specific information about providing care for older survivors. Open-ended questioning was also used to enable interviewees to elaborate on their own experiences and provide examples of providing aged care services for older survivors.

## **Focus groups with aged care workers**

Focus groups were conducted with aged care workers recruited from organisations providing aged care services for older Holocaust survivors or Cambodian survivors in the selected LGAs.

## **The sites**

Ninety aged care workers from seven organisations participated in 10 focus groups. Three focus groups were held with staff working in residential care (two with Jewish Care staff and one with agency-employed personal care attendants); three were held with staff providing direct home care services in older people's homes (Jewish Care, City of Port Phillip and City of Greater Dandenong); two were conducted with staff working in planned activity groups (Jewish Care and City of Whitehorse); two were held with Jewish Care case managers; and one was conducted with clinicians from the Caulfield Aged Care Assessment Service (ACAS).

## **Field issues**

Focus group discussions were held in meeting rooms at the offices of each organisation, with the exception of a focus group for workers from an aged care agency that provides non-permanent personal care attendants to a Jewish Care residential care facility (RCF). This focus group was held at Jewish Care. Focus groups were held during working hours with full involvement of the manager of the service in recruiting the staff. Many focus groups participants, particularly the personal care attendants in residential care and the home help workers in community care, reported having few

opportunities to talk about this aspect of their work. Some felt that by talking about it with other workers they were able to better understand their own experiences and their own reactions to those experiences.

### **Theme list**

The focus group theme lists were developed using information collected in the scoping study and the community consultations (see Appendix 2). The participant information and consent form (PICF) was emailed to service managers, who distributed copies to staff in advance of the focus group discussion. This gave participants the opportunity to read the information and decide whether they wanted to attend. Each focus group ran for one hour, beginning with a brief introduction to the project, an explanation of the structure of the focus group session, and confidentiality and use of the data.

### **In-depth interviews with older survivors and family carers**

The purpose of the face-to-face interviews with older survivors and family carers was to learn about their experiences of receiving care in residential and community aged care settings. Collection of information from the older survivors themselves helped give meaning to the experiences of the past and shed light on how they are impacting on clients' experiences of aged care services in the present. Interviewing was completed when 'saturation' of the emerging themes was achieved.

In-depth interviews were conducted with 22 community-dwelling older survivors who were receiving aged care services at the time of the interview. Seventeen of these interviews were held in the older people's homes in Melbourne, four interviews were held at a Cambodian planned activity group in Sydney and one interview was conducted by phone. Twelve of the 22 interviewees were Holocaust survivors, nine were older Cambodian survivors, and one was an older Sudanese survivor. Nineteen interviewees were women and three were men. Fourteen interviews were conducted in English, and eight of the nine interviews with older Cambodian survivors were conducted with a Khmer-speaking interpreter.

Interviews were conducted with eight adult daughters (and in one case a granddaughter) of older survivors. Six interviewees were carers of Holocaust survivors living in residential care and two were carers of older Cambodian survivors living in the community.

### **Field issues**

Gaining access to the field and recruiting older survivors was a lengthy process. Reluctance to be interviewed is perhaps to be expected from this client group. The Jewish Care community services managers assisted in recruiting Holocaust survivor interviewees. Other older survivor interviewees were introduced to the researchers by a person (usually a service provider) who was known and trusted by the older survivor. Some family carers were recruited by speaking at resident and family meetings in residential care facilities (RCF) and at Planned Activity Groups (PAG).

### **Theme list for in-depth interviews with survivors and family carers**

Based on findings from the pilot study and the community consultations conducted in the first stage of the project, a theme list for older survivor interviews and family carers was developed. These themes are outlined below:

1. Older survivors' experiences of:
  - Increasing frailty and dependency
  - Accessing aged care services
  - Using community care services
  - Transition to residential care/living in residential care.
2. Older survivors' views on what aged care workers should know about working with older survivors.

A set of open-ended interview questions was developed from the theme list. The interviews were run in a conversational style using traditional in-depth interviewing techniques. The interviewers tried to elicit aged care experiences that survivors/families have found difficult or upsetting and older survivors' and/or family carers' perspectives about positive aged care experiences. It was found that the in-depth interview approach was not very successful with older Cambodian interviewees. Translators who accompanied the researchers to interviews indicated that the open-ended questions were in general perceived by the older Cambodian interviewees to be 'western' types of questions to which this group was not accustomed. This experience led the researchers to develop a new set of closed-ended questions based on the theme list was developed (See Appendix 2).

## **Recording and informed consent**

All participants gave consent to use the information for research purposes. All focus groups and most in-depth interviews were digitally recorded. Participants were asked to sign consent forms before the digital recorder was turned on. Recorded interviews and focus groups were transcribed by a professional service. Where interviews were not recorded, written consent was gained to take handwritten notes.

## **Coding and data analysis**

Qualitative data analysis strategies were used to code the data and condense the codes into themes. The interview transcripts were coded with the assistance of NVivo software. Several stages were involved in the data analysis.

- Stage 1: Researchers listened again to the recorded interviews and re-read the entire transcript of the interviews while correcting errors in the transcripts and writing down thoughts in the margins.
- Stage 2: Researchers examined the transcripts for salient categories of information supported by the text (Creswell, 2007; Strauss, 1990). Concepts and categories emerged and frequently changed over the course of the analysis. Category names were kept tentative, since some categories eventually 'died out', new ones emerged and some merged. Overall, this is a process of reducing the database to a small set of themes that characterise the process or action being explored.

- Stage 3: In the next stage, a process similar to axial coding was adopted (Creswell, 2007; Strauss, 1990), which is the process of interconnecting categories by positing relationships between them. The purpose of axial coding was to examine 1) ways in which older survivors' trauma experiences may impact on their aged care experiences, 2) the experiences of formal carers in providing care for older survivors.
- Step 4: In the final analysis stage, the coded categories were integrated by relating them to the key construct of the research—providing optimum aged care services for older survivors.

## **Chapter 3: Research Findings**

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The research findings are divided into four sections. In each section the major themes and sub-themes to emerge from the process of thematic coding are identified, discussed and illustrated with quotes from the interviews and focus groups. The major themes are summarised below:

### **Section 1: Genocide and mass trauma**

- Genocide and mass trauma experiences
- Long-term impacts of trauma

### **Section 2: Genocide trauma and ageing**

- Living with memories of the past
- Declining health
- Accessing community care services
- Moving to residential care

### **Section 3: Older survivors' experiences of aged care services**

- Practical, social and emotional support
- Opportunities for social participation and meaningful activities
- Potential reminders of past trauma in the aged care environment

### **Section 4: Aged care workers' experiences of providing care for older survivors**

- Recognising older survivor clients
- Comprehending trauma experiences and responses
- Encountering challenging situations
- Feelings about working with Holocaust survivors
- Developing effective carer–client relationships

## **Section 1: Genocide and mass trauma**

### **Theme 1: Genocide and mass trauma experiences**

Many project participants (including aged care workers, family carers and older survivors themselves) considered awareness of the kinds of unimaginable experiences that older survivors may have experienced in the past as a necessary step towards understanding them as clients in aged care. While older survivor interviewees were not asked specifically about their war-time experiences, many spoke about aspects of these experiences in the context of questions about ageing and using aged care services in Australia. Some stories about older survivors' earlier-life traumatic experiences were related by family carers and aged care workers. These experiences are grouped into three sub-themes—acts of organised violence, destruction of families, and chronic fear and anticipation of death—and are illustrated in Table 3 by selected quotes.

#### ***Sub-theme 1: Acts of organised violence***

Acts of organised violence witnessed or experienced by older survivors included: executions, mass killings and beatings; prolonged periods of living in hiding; internment in concentration camps, or forced labour camps; and deprivation of food, shelter, medical care and humane living conditions (see Table 3, Quotes 1 to 7).

#### ***Sub-theme 2: Destruction of families***

Accounts were given by older survivors of the deaths of their husbands, children, parents and siblings (see Table 3, Quotes 8 to 10). Some older survivor interviewees were sole survivors of large extended families. A number of the Holocaust survivor interviewees had lost their parents as children. According to the Cambodian interviewees, the Khmer Rouge's deliberate strategy of separating family members has disrupted traditionally very cohesive family structures and patterns of elder care.

#### ***Sub-theme 3: Chronic fear and anticipation of death***

Enduring years of fear and anticipation of death was a common theme to emerge from the data. An aged care worker had cared for a non-Jewish nursing home resident whose father helped Jews escape from the Nazis during the WWII. The resident's father had a gun with five bullets and told her if they were caught it would be better for him to kill his family and himself than to be sent to a concentration camp. The resident said that she still 'fights that memory' all these years later (see Table 3, Quotes 11 and 12).

**Table 3: Genocide and mass trauma experiences**

<u>Sub-theme 1: Acts of organised violence</u>	
1	<i>There was a wood heap near the [concentration] camp and periodically German guards allowed people to collect wood so that they could cook food but it was a game of Russian roulette – the guards would randomly call out ‘stop’ and then shoot the person who happened to be collecting the wood at that instant – a man was shot dead immediately in front of me. [Holocaust survivor]</i>
2	<i>She said she could sew cause she knew that was going to help her survive so she was put in to a factory and as a machinist, and she learnt fast...(the Nazis) came in towards the end of it and they shot just about everyone in the factory. And she played dead. She had bodies on top of her. She told us that was how she survived. (Daughter-in-law of a Holocaust survivor)</i>
3	<i>Everything that might give us away we buried (clothes, ID, army clothes). That night some army clothes were found and the owner of the clothes was found and executed on the road. [Older Cambodian describing a forced march out of Phnom Penh]</i>
4	<i>One of the Khmer Rouge soldiers asked for (my husband’s) jewellery and when [he] did not give him the jewellery he was arrested and he was tortured. This injury is still there and his scalp is dented in (and he has) many problems. [Older Cambodian survivor]</i>
5	<i>(One of my clients) sat on the banks of the river and watched the Germans actually drown her whole family. You know to see her brothers and sisters put into the water and held down until they’re dead. [Community care manager]</i>
6	<i>(My friend was a little child when she) saw with her eyes the Germans shoot her mother... she’s a very nervous person...she didn’t accept home help ..... she was frightened when the worker came to her door, maybe her memory come back...[Holocaust survivor]</i>
7	<i>So that day they come with the gun, they kill the people in the country. So we run. We run to Ethiopia ... The Arab came after us and killed the people and so we run but we got other people there died and we run, one month we are running, no water, no food, no anything with mosquitoes and snakes. [Older Sudanese survivor]</i>
<u>Sub-theme 2: Destruction of families</u>	
8	<i>Life in the past it’s very difficult in the Pol Pot regime. My husband and I worked so hard, and when Pol Pot comes, it’s all gone. Everything’s gone. My house and all my family, all gone, finished, killed, all died. Due to Pol Pot I’ve lost all my family. I just found out I’ve got a sister alive in America, recently. [Older Cambodian survivor]</i>
9	<i>There was nobody... after the war, after the camp. You haven’t got anybody. You haven’t got a single scrap of anything, nothing. You are a person without a past....that’s how I felt sometimes. Nobody knows anything about me and I haven’t got a single thing to show. My husband as a little set of fruit knives from his home, somebody he knows [kept it during the war] and he got it back. A little something from his home. I haven’t got anything. [Holocaust survivor]</i>
10	<i>No one left alive...there was nobody, it was all finished, all killed. Not a single soul ...I lost everyone. We had such a wonderful family...I’ve got a photo of my parents...I am very lucky to have the photo...My father sent me a few photos to camp... I was frightened that they would shoot me if they find that I’ve got photos. So I cut them out and pinned them underneath what I was wearing. [Holocaust survivor]</i>
<u>Sub-theme 3: Chronic fear and anticipation of death</u>	
11	<i>During KR [Khmer Rouge] time no one could sleep....during that time that I was in the killing place people were taken out and killed every night. [Older Cambodian survivor]</i>
12	<i>Life is not good also in the [refugee] camp because most people in the village they don’t like [us] ...so always they kill us in the night. These years we are staying in the camp we are attacked ... Every night there was gun; they would come and kill you with the gun. For 13 years we are attacked. [Older Sudanese survivor]</i>

## **Theme 2: Long-term impacts of trauma**

Project participants (including the older survivors) spoke about the impact of past traumatic experiences on their lives (see Table 4). Most Holocaust survivors acknowledged the long-term psychological impacts of the Holocaust (see Table 4, Quote 1).

Older Cambodian interviewees tended not to discuss psychological effects of the Pol Pot years. Some spoke of being ‘trapped in feelings and unable to express them’. One older Cambodian woman felt that because the past is always with her and others who survived the genocide, older Cambodian people can experience frequent mood swings, and another older Cambodian woman spoke of being socially withdrawn as the result of her husband being tortured both by the Khmer Rouge and guards in the Thai refugee camp more than 30 years ago (see Table 4, Quote 3). Some described physical injuries and chronic health problems that they or their family member(s) continued to suffer from as being a result of their genocide experiences.

Sleep disturbance and nightmares were the most commonly mentioned post-trauma issues mentioned by the older survivor interviewees (see Table 4, Quotes 4, 5 and 6). Aged care and welfare workers and family carers discussed a wide range of psychological and psycho-social impacts of the genocides on the lives of older survivors. Interviewees discussed the life-long tendency for older survivors to distrust or fear people (see Table 4, Quote 2). A Cambodian community worker suggested that some people may even fear their own family and friends and attributed this to time spent in labour teams during the Pol Pot years when individuals often ‘dobbed each other in to please the guards’. The daughter of a Holocaust survivor also described her mother’s long-term distrust of people.

This distrust typically applies to older survivors’ attitudes towards government services in general. Cambodian service provider interviewees felt it was better if the service was recommended by someone who the older person knew. They also suggested that older Cambodians could be afraid of assessment forms because they were spied on during the Pol Pot years. A PAG activities coordinator commented on the need for aged care workers to understand that, based on their upbringing and the culture of the former Soviet Union, older people from this background usually have a deep distrust of the system and bureaucracy (see Table 4, Quote 7).

Other trauma responses discussed by project participants included fear of taking risks and hyper-vigilance. A Cambodian health professional attributed the tendency to avoid risk to the Pol Pot years, when risk-taking was extremely dangerous.

Aged care workers also discussed the difficulty that some older survivors face when having to make decisions. A Cambodian welfare worker suggested that this is the result of years of living with fear and the daily threat of death, where the only way to survive was to have no opinion, no expectations or hopes and to do as you were told. Similarly, a family carer of a Holocaust survivor described her mother-in-law’s life-long inability to make decisions.

Ongoing and worsening guilt about surviving was another common theme for both Holocaust survivors and older Cambodian survivors. A Cambodian housing worker suggested that guilt about surviving is possibly the most significant invisible sign of traumatic stress. He noted that many older Cambodians ‘carry a sense of guilt’ either because they survived the Pol Pot years, or they believe that they contributed to the deaths of those who did not survive.

**Table 4: Long-term impacts of trauma**

1	<i>We were all damaged, there's not one person who survived the Holocaust who is not...A survivor is only the one who stayed alive but we didn't survive the trauma. [Holocaust survivor]</i>
2	<i>She never trusted anyone, even her son and that obviously all comes from the war. [She] hated doctors...I'm sure because of what they did to so many...She always wanted me to come with her to the doctor for anything that was personal... It's almost like me being the Mother and has a little girl that, you know, I'm frightened...Police I don't think she was too thrilled about them. Because the people in uniforms...probably have a big traumatic effect on her. [Daughter of a Holocaust survivor]</i>
3	<i>We prefer not to have anyone come to the house because he doesn't like to have anyone around. Even now he [husband] likes to sit by himself. [Cambodian survivor]</i>
4	<i>...[my husband] still refuse to go to Cambodia...He will not face the Cambodians...For him he was so traumatised up to this day...[said] he doesn't want to go and face his demons at Cambodia again. He said he's had enough of it...He suffered long enough, he doesn't want to have the bad memory...He still have dreams about Pol Pot arresting him. Want to send him to the killing fields... they attempt to kill him but now he wakes up shaking. [Older Cambodian survivor]</i>
5	<i>Sometimes at night time, you can't sleep, you think about [the Holocaust] then during the day not so much because it happened 60 years ago...a lot of things, they come back to you at night. [Holocaust survivor]</i>
6	<i>I don't know up to now [where my son is]. That for me, I not sleep always ... I don't know where he is now. So it is hard for me. I am always thinking my son ... We don't know if he is alive, we don't know. I don't know ... always thinking where is my son. [Older Sudanese woman]</i>
7	<i>The only way to survive [in the former Soviet Union] was to deceive the system or avoid the system and to rely on family networks. [PAG activities coordinator]</i>

## Section 2: Genocide trauma and ageing

### Theme 1: Living with traumatic memories

Living with traumatic memories emerged as a key theme in conversations with older survivors. Most older Cambodians were unable to forget the past, despite their strong belief that the ‘past’ should be left ‘buried’ and ‘forgotten’ (See Table 5, Quote 1). Although Holocaust survivors tended to believe that the past should be remembered so that the tragedy of the Holocaust could never happen again, the majority continued to struggle with the traumatic memories and the sadness (See Table 5, Quotes 2 and 3).

Older survivor interviewees often experienced the contradiction of wanting to remember and at the same time wanting to forget past events. There appears to be an internal conflict of wanting to forget the traumatic experiences but not wanting to forget loved ones who did not survive. For some older survivors, reminders of loved ones can be distressing while others have found an ‘internal’ place to store these memories. The tendency to live in two worlds, an external and an internal world (which is documented in the literature), was described by a number of interviewees (see Table 5, Quotes 4 and 5).

Commonly, survivors tried to put the traumatic past behind them by not talking about it. Many older survivor interviewees revealed that they had not talked to their children about the past in an attempt to spare them from the horror and sadness that they had suffered (see Table 5, Quote 6). Many adult children of Holocaust survivors and older Cambodian survivors confirmed that their parents had not told them much about the past. In some cases, these children were aware of their parents’ stories more by implication, in the form of nightmares.

It was common for older survivors to experience current everyday situations, objects, places or sensory stimuli as reminders of past trauma. For example, a Holocaust survivor spoke of a recent cold day when wearing thongs in her garden had reminded her of a specific day during the war when she stood barefoot in roll call in the concentration camp (see Table 5, Quote 7). A Cambodian-born social worker explained that he still felt uncomfortable being in a forest because of the killings that occurred in that environment during the Pol Pot period.

Some older survivors spoke of how they coped with traumatic memories in old age. For some older survivors (both Holocaust and Cambodian) writing about their life has helped them to face the past. Some older survivors found that talking about the past with others who went through similar experiences was better than trying to avoid it, while others were not willing or able to talk about the past.

Some spoke of being helped by their religious beliefs. A Cambodian welfare worker explained the importance of going to the temple ‘to heal’ for many older Cambodian people and that many became more observant as they aged. One older Cambodian survivor said her belief that Karma had caused the genocide helped her to live with the past. Another older Cambodian survivor spoke of focusing on her Christian faith (See Table 5, Quote 8). Many Holocaust survivors said that focusing on the next generation and living for those who ‘were not so lucky’ gave meaning and purpose to their lives (See Table 5, Quote 9).

**Table 5: Living with the memories**

1	<i>I want to try to forget but how can you...the stories seem to follow, the issues that happened... [Older Cambodian survivor]</i>
2	<i>Sometimes out of the blue will come something back to me or I didn't think about it for many, many years...It comes back. As much as I want it to stop, I really want it to stop, I don't want these items. Let's stop, finish, no more. [Holocaust survivor]</i>
3	<i>Because I haven't got any photographs. I sometimes want to go to remember my mother's face and I can't. I can see like a part or piece. I have lost my mind there. It's very hard [I feel] anger and frustration and then sad. Some days are very, very sad...' [Holocaust survivor]</i>
4	<i>It is a yearning, people say put it behind you; never, you can't. What we do we internalise it, we didn't put it behind, you lived with it and at times I didn't want to share it with my children, I didn't want to infect them with the trauma. So I got them involved in everything beautiful and told them everything beautiful about the world, about the people, about everything but I carried it...I had a little box in my chest and carried it with reverence and thought of it that way and I said I'll never part with that I have no family, I have no feeling of belonging, I didn't know where I came from unless my mind told me. [Holocaust survivor]</i>
5	<i>It's just there. For as long as I live, I know people that I love live in my heart. They are always with me...the past is with me. This is not something that you can sort of forget. It's with you even subconsciously, all the time. And I don't want to forget. [Holocaust survivor]</i>
6	<i>Because we hide from the society...because we afraid of... that they are being looked down on us, so we rather keep things ourselves. I just explain to you about my family issue. None of the family here knows. Because those are things that we don't talk about... We are upset because we are a broken family... Usually Khmer people don't talk about things like that. [Older Cambodian survivor]</i>
7	<i>One day it was so cold here and I had thongs on and I asked myself. 'How was it in my camp on 1<sup>st</sup> May [during the war] people went without shoes. [The guards] said 'it's summer, you don't need shoes'. And we were standing barefoot during the roll calls...It was in a very muddy part of the country...I was walking barefoot when I was 20 without shoes on 1<sup>st</sup> May. [Holocaust survivor]</i>
8	<i>I try not to remember the past I only think about God. I try to just think about God, I don't want to think about the past. I want to forget the past...my faith in God helps – what helps me get through my life. [Older Cambodian survivor]</i>
9	<i>The purpose (of writing my book) was for the ones who didn't have the chance to do what I did...how many wonderful talents were killed, they didn't have their chance to shine, they didn't have their chance...But I want to talk about them, I want to tell the world that they have been...and their life was cut short because they were killed. [Holocaust survivor]</i>

## Theme 2: Declining health

The research found that declining physical or cognitive health and increasing dependency can cause intense anxiety for some older survivors. Family carer and aged care worker interviewees reported that some Holocaust survivors have intense fears of ageing and illness and under-report illness. These fears were considered to be related in part to Holocaust survivors associating their own experiences of ageing with the fate of the elderly and the ill during the Holocaust. The daughter of one Holocaust survivor felt that her mother's 'paranoia' was exacerbated when she was unwell.

Project participants suggested that being very active in the post-war years had helped many older survivors cope with the losses and trauma of the past; however, as older survivors became less engaged in family and work commitments and their health declined, traumatic memories from the

past, which they may have successfully contained, started to intrude more in their lives (see Table 6, Quotes 1 and 2).

Most family carer interviewees discussed the distress that older survivors with dementia can experience when they revert to the past (see Table 6, Quote 3). The evidence suggested that reverting to the past was not always distressing for an older survivor with dementia. One family carer, whose uncle had been a resistance fighter, felt that when her uncle was reliving the past, he returned to being a brave fighter whose goal was to protect the people around him (see Table 6, Quote 4).

For older survivors, medical or dental procedures or spending time in hospital may be reminders of intensely life-threatening experiences. Many concentration camp survivors, for example, either experienced or witnessed painful and inhumane medical procedures or experiments. Research findings suggested that the association older survivors may make between a current health care setting and the terrifying experiences of the past could intensify the older survivor patient's feelings of pain or discomfort, lack of control, anxiety about outcomes, and fear of the future. A Holocaust survivor explained that when she was in hospital '...all the worst memories seem worse' with the blood tests reminding her of being tattooed with a number on arrival at a concentration camp<sup>1</sup> (see Quote 5).

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<sup>1</sup> Tattooed numbers was used by the Nazis as a system of identifying concentration camp prisoners. This procedure was done roughly and without anaesthetic <http://www.ushmm.org/wlc/en/article.php?ModuleId=10007056>

**Table 6: Declining health**

1	<i>The trauma comes back, the older you get the more you think about it, you can't help that. When you're young and you're busy raising children and meeting friends and making a home and finding a job but when you get older all this trauma comes back you can't help it...It's [the past] always there...more now than it was before. Because you lost your sense of purpose...you were married, you have your children, your children have children, to a certain degree it has been accomplished and you feel you're just fading away a bit, you're just taking it easy but you can't take it easy because when you take it easy you get absolutely overwhelmed with what happened to you...[Holocaust survivor]</i>
2	<i>You lose your health and you don't have good sleep at nights so when you wake up what do you do? Think! And when you are unwell and when you are single, when you are alone, when you're isolated, what do you think? Of your background, of your family...There's not a day now that I don't think of them. When I was very busy I always did but it was just easier because I was so busy. [Holocaust survivor]</i>
3	<i>She can't snap out of these tragic events...People who actually are not alive anymore...yesterday she started to cry. She's talking about her brothers and sisters... [Daughter of Holocaust survivor]</i>
4	<i>One time in the nursing home he yelled out and told everyone to get down on the floor. We understood his history, his need to protect other people and that what was his reality at that moment in time. So, we [the family member present in the room] got down on the floor with him. [Family carer of a Holocaust survivor]</i>
5	<i>I have very bad vein and to take blood [brings back] the memories of the tattoo still. [In hospital ] I just was frightened and some of them, apart from one Chinese girl whose name was Helen, she was the only one who knew how to talk to me. She said, 'don't worry it won't hurt'. Just a simple sentence like that. Like to a child. I was so happy when Helen was on duty. [Holocaust survivor]</i>

### **Theme 3: Accessing community care services**

As older people's health care needs become more complex, their need for care and support increases. We were interested in the different participants' views about whether earlier-life trauma experiences had influenced older survivors' willingness to take up community care services.

Older survivor interviewees did not generally link prior experiences of trauma with their attitudes towards aged care services; however, formal and informal carers noted that older Cambodian and Holocaust survivors tended to be suspicious of strangers, which could be a barrier to accepting formal care in the home (known as 'home help' by the majority of clients). Interviewees mentioned a number of cases where care was put in place but the older survivor client did not open the door for the aged care worker who came to provide the care. In one case, a Holocaust survivor explained that the aged care worker reminded her friend (the client) of a concentration camp guard.

In the case of older Cambodian survivors, both the survivors themselves and Cambodian key experts felt that one of the main barriers to accessing services was the cultural expectation for older people to be cared for by the family. Interviewees suggested that in the Cambodian community aged care services were generally not seen as an 'entitlement' but rather as a 'last resort'. Most frail older Cambodians live with their family and are cared for by their children. In the words of one welfare worker experienced with working with this community, 'accepting formal care is seen as an insult and an assault on the goodness of the family'. Cambodian interviewees also suggested that families' concerns about 'what the community might think' played a significant role in not taking up formal care. These interviewees suggested that social and recreational activities were more likely to be

accepted than home help; first, because they did not threaten the integrity of the family and second, because it was understood that in Australia older Cambodians could find it difficult to get to a temple or any other place without their children.

Cambodian older people and their families also face considerable difficulty accessing community services due to language barriers and lack of knowledge about available services. A Cambodian PAG coordinator noted that the older Cambodian women attending the PAG did not use home help services until they reach a crisis point and had no other choice. Interviews with older Cambodian survivors and Cambodian-born carers revealed that it is common for Cambodian families to sponsor a relative to come out from Cambodia to care for older family members.

Changing one's identity is a commonly reported strategy used by displaced people to facilitate resettlement. Family carers and aged care worker interviewees spoke of Holocaust survivors and Cambodian survivors who had changed their age, name and occupation in order to survive both during the genocide period and during their time in displaced persons' or refugee camps. Many refugees had believed that resettlement applications were more likely to be successful for young people. Key experts reported that older survivors whose official papers on arrival in Australia stated that they were younger than their actual years, many years later, have difficulty accessing government-funded aged care services when they need them. Furthermore, older Cambodians who entered Australia with false identities can have difficulty sponsoring family members to come to Australia to provide family care due to problems proving their relationship with the family member in Cambodia.

#### **Theme 4: Moving to residential care**

Key experts and family carers described the move from one's home to a residential care facility as a very painful transition for Holocaust survivors. They suggested that moving to residential care, which involves giving up most of the possessions that have been accumulated in the new country, can take on enormous meaning for older survivors who arrived in Australia with nothing. Packing one's things into a few suitcases for the move to residential care was thought to be reminiscent of earlier times when people were forced to leave their homes with only a few possessions. Key experts suggested that older Cambodians are generally highly resistant to the idea of moving to residential aged care. They were reported to be concerned about premature death, not being visited by family members, and 'starving to death' due to a lack of suitable food.

The potential for some aspects of life in a residential care facility (RCF) to be distressing for older survivors also emerged from the data. Some aspects of living in a RCF may be reminiscent of earlier-life experiences of imprisonment. Some of the issues that were raised were: being dependent on others for one's basic needs; being surrounded by unfamiliar people; having one's daily routines dictated by rosters and processes; and being exposed to people who may be ill and dying.

At the time of the study the researchers were unable to locate any older Cambodians currently living in a residential care facility in Melbourne. Due to common past experiences of organised violence against individuals, families, and communities, older Cambodian survivors could be expected to experience similar difficulties with some aspects of living in residential care as Holocaust survivors.

### **Section 3: Older survivors' experiences of aged care services**

Themes that emerged from the interviews with older survivors and family carers about using aged care services were categorised into three major themes:

1. Practical, social and emotional support.
2. Opportunities for social participation and meaningful activities.
3. Factors in the aged care environment as potential reminders of past trauma.

#### **Theme 1: Practical and emotional support**

Older survivor interviewees spoke of their appreciation of and satisfaction with the practical support they were receiving. In general, they felt it was important for the aged care worker to be gentle, warm and cheerful, and some interviewees stressed that it was important for an aged care worker 'not to be bossy'. Aged care workers and family carers suggested that older survivors may be 'extra' sensitive to the way they are treated because of their prior experiences of abuse and degradation (see Table 7, Quote 1). The evidence suggested that home help should be provided by a carer that the older survivor has been able to develop a 'close' working relationship with (see Table 7, Quote 2).

Some family carers felt that aged care workers should treat older survivors like their own family member in order to reassure them that they are safe. On the other hand, for one family carer, who was living with her older survivor parent, it was important for aged care workers to be uninvolved in the 'family's business'.

Most Holocaust survivors thought that aged care workers should know they are Holocaust survivors and should be generally aware of the events and experiences of the Holocaust. The older Cambodian interviewees, on the other hand, generally did not think that aged care workers needed to know about traumatic events of the past in Cambodia.

#### **Theme 2: Opportunities for social participation and meaningful activities**

While not all older survivors were interested in attending an organised group or any other type of activity with other older survivors, many of the interviewees described the positive impact that participating in planned activities had made on their lives. The reported benefits (which are illustrated in Table 7) included:

1. Facing memories and losses of past trauma in a safe environment (see Quotes 3 and 4)
2. Giving meaning and purpose to one's life (see Quotes 5 and 6)
3. Overcoming social isolation (see Quote 7).

Family carers and activities coordinators also spoke of the importance of social participation for older survivors. While one Cambodian community leader believed that the older survivors had put the events of the past behind them, most Cambodian community workers felt that the past was ever-present and that Cambodian Planned Activity Group (PAG) can provide older people with ways to cope with the late-life impacts of the trauma.

**Table 7: Practical, emotional and social support**

Theme 1: Practical, and emotional support	
1	<i>We all like to be treated well ... [but] people who have gone through trauma and really significant loss and experiences are even super sensitive to the way they've been treated. [Daughter of a Holocaust survivor]</i>
2	<i>The survivors were all damaged and if the carer is gentle enough and is understanding that is a great help. I can see the difference, not just coming and cleaning that's not enough, it's cleaning my pain and my soul is more important. I'm much more appreciative of carer who come and sit down and have a cup of tea with me and say how are you and give me a hug and give me a kiss much more than when she will clean my house — and I love to have the house cleaned I can tell you that much. [Holocaust survivor]</i>
Theme 2: Opportunities for social participation and meaningful activities	
3	<i>Sometimes we do talk about it... we are lucky that we alive and together. Because in the Pol Pot time, can't even sit in a pair to talk to one another. You were all separated, individually....we discuss our fears, what we went through, and we happy that now we got each other here to talk about it. [Cambodian older survivor]</i>
4	<i>Here you're free to talk about it... at the moment Centrelink look after us and we don't worry about who is recording us! [Cambodian survivor]</i>
5	<i>There's a little Russian poem...it's the Autumn of Life... thousands of pains and memories that come flooding back...Some hair going grey and the rain falling and all those questions that remain unanswered. That is pretty much what the autumn of life is but these people [staff at the Planned Activity Group] ...pretty much try to cheer us up and they say to us, well don't close down, don't shut out, just go out, go to the world, look at things, try to be interested in things. [Holocaust survivor]</i>
6	<i>It's important to make sure that they have ongoing activities, so they don't think while they are sitting and doing nothing, and this is especially for Holocaust and trauma residents. If they are just left with staring into air or space then they start thinking and that can cause distress. [Daughter of older survivor]</i>
7	<i>I did not want to be involved with a crowd and enjoy life because I have been through so much. Because of the information and support I gave it a chance. I joined the group. Since I have been involved I see the amazing and important things that have changed my life. I can't wait to join this group every week, I look forward to it. I want to be part of this group – it is a new life for me. I am nearly 70 years old, but now I feel 50 years old. The group makes me feel young. I feel that there is a bright future for me now; I won't get bored with my life. [Older Cambodian survivor ]<sup>2</sup></i>

### Theme 3: Potential reminders of past trauma in the aged care environment

Older survivors were asked whether they had had any difficult or negative experiences in an aged care environment. Family carers and aged care workers were also asked about their perspectives on the difficulties encountered by older survivors in aged care. A range of factors in the aged care environment emerged as potential reminders of past trauma for older survivors. These reminders, often referred to as triggers, were found to provoke negative feelings in some older survivors such as fear, anxiety, lack of control, and humiliation. The emerging findings are categorised into four sub-themes:

1. The social environment
2. Care or support tasks

<sup>2</sup> Quote from 'Inner East Social Inclusion project' (Teshuva & Reid, 2010)

3. Planned activities
4. The physical environment.

### ***Sub-theme 1: The social environment***

Focus group participants and family carers spoke of older survivors being particularly vulnerable to aged care workers whom they perceived as being bossy.

Interviewees spoke of situations in which the physical appearance or personal characteristics of an aged care worker had precipitated conditioned fear responses in older survivor clients (see Table 8, Quote 1).

### ***Sub-theme 2: Care or support tasks***

Being assisted with personal care is difficult for any aged care client to accept. This aspect of care involves not only private areas of the body but also psychologically and emotionally sensitive aspects of who we think we are and how we present to the outside world. Sensitivities around nudity and touch, exposure and shame are intimately associated with personal care. David and Pelly (2003) described how for survivors of concentration camps, invasions of personal boundaries and having no privacy and few or no opportunities for maintaining personal hygiene, can result in long-lasting feelings of humiliation, degradation and shame. This research confirmed that these feelings may be very close to the surface more than 60 years later and can be re-ignited by insensitive handling of older survivors' personal care. A number of Holocaust survivors spoke of their distressing experiences of being assisted with personal care in aged care and health care settings that were reminiscent of humiliating experiences during the Holocaust years (see Table 8, Quotes 2 and 3). Aged care workers and family carers also spoke of the distress of some female older survivors when they were assisted with personal care by a male carer. The distress was attributed to the humiliating experiences (including rape) inflicted by their persecutors during the genocide period.

As well as provoking feelings of shame and humiliation, personal care situations can activate feelings of extreme anxiety and fear for personal safety. Family and formal carers described older survivors' conditioned fear responses if staff 'physically intruded' on them. The daughter of Holocaust survivors described her parents' extreme agitation if staff 'hover over' them. The terror that some Holocaust survivors felt when being showered emerged from interviews with family and formal carers. This fear relates to the mass murder of Jews in gas chambers during the Holocaust.<sup>3</sup> A family carer of a Holocaust survivor with dementia described her mother-in-law's first experience of a shower after she was admitted to residential care (see Table 8, Quote 4).

Formal and informal carers also spoke of the potential for an aged care assessment to be anxiety-provoking for older survivors. First, an assessment may raise questions about family members and the availability of family support. Invariably older survivors are highly sensitive about these issues. Second, assessment can stir older survivors' fears of official documentation and being asked to divulge personal information (see Table 8, Quote 5).

Food was a major issue of concern for many of the older survivor interviewees. Older Cambodians referred to the Pol Pot years as 'the starvation period'. Holocaust survivors pointed out that a single

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<sup>3</sup> In concentration camps, inmates were herded into gas chambers having been told that they were to have a shower. They were stripped and pushed all together into rooms. The doors were locked and gas came out of the shower heads. Hence, showers meant death.

mouldy scrap of bread could represent the difference between living and dying. Cambodian project participants raised a common fear that older Cambodian people who went to residential care were at risk of ‘dying of starvation’ because they would not be given suitable food. Some older survivor and family carer interviewees felt that aged care workers who had not experienced extreme hunger may not understand older survivors’ fear of hunger and may be judgmental about clients who hoarded food and kept food that had gone off. One Holocaust survivor interviewee described the experience of a friend who was living in residential care (also a Holocaust survivor). When her friend asked the nurse on duty for something to eat in the late afternoon she was told to wait until dinner time. The interviewee felt that the nurse should have understood how distressing it was for her friend (who had experienced starvation during the war) to be forced to wait for food.

Cambodian and Jewish key experts suggested that the cessation of feeding especially towards the end of life is completely intolerable for some of families of older survivors. It may be seen as allowing one’s parent to starve to death in a care facility after having survived starvation during the genocide. The daughter of a Cambodian older survivor described why she took her mother home two days after her admission to residential care (see Table 8, Quote 6).

Paid and family carers also suggested that food can have a number of other meanings for older survivors. For those with gastro-intestinal tract problems including reduced sensitivity to smell and taste, or a dry mouth, vitamised food may remind them of times in the camps when food was barely edible. On the other hand, a home-cooked, traditional meal may be a sad reminder of happy pre-war times. This was the experience of a residential care activities coordinator working with a Polish Holocaust survivor resident. This resident had lost his entire family and had been isolated from the Jewish community since arriving in Australia. She had offered to cook traditional home-made Polish food for him but was told by the resident’s wife that this would make him feel bad because it would remind him of his mother and her cooking.

### ***Sub-theme 3: Planned activities***

The findings highlight the importance of staff being aware that older survivor clients may be sensitive to activities or discussion topics that related to their personal experience of trauma. Any type of activity—health promotion, religious or cultural celebrations, and art, music or life writing sessions—can bring up frightening or painful memories from the past. For example, a common activity in PAGs is to assist older people to access health and aged care services. One activities coordinator found that a participant became very distressed by the mentioning of dental services (See Table 8, Quote 7). Another Holocaust survivor had been highly distressed by the use of gold stars in an art therapy session. This distress was likely to have been related to German government's policy during WWII of forcing Jews to wear yellow, star-of-David shaped badges.<sup>4</sup> While many of the older survivors (including one older Cambodian interviewee) spoke about the positive impact of writing their life stories, one activities coordinator spoke of a Holocaust survivor client in residential care who was highly distressed by the suggestion that he make a ‘this-is-your-life’ album.

Family carers and key experts spoke of the need for care providers to be aware of the effect that special celebrations such as religious festivals can have on older survivors. On one level these celebrations later in life can bring enjoyment and comfort. At the same time, however, they can cause distress because they evoke memories of the loved ones who did not survive (see Table 8, Quote 8).

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<sup>4</sup> This was a tactic aimed at isolating the Jews from the rest of the population. Jews caught not wearing the badge could be shot. It enabled the German government to identify, concentrate in ghettos, deprive, starve, and ultimately murder the Jews in European countries under its control.

Furthermore, the data show that because each individual survivor's trauma experience was unique, what causes distress in one client may have no effect on or may be a source of comfort for others. Several examples emerged from the focus group discussions— the use of pet therapy has been reported in the literature to cause great distress for some former concentration camp or prison camp internees (David & Pelly, 2003); however, we found that some older survivors were actually very fond of dogs because of their experiences of being protected by dogs during the war. A Holocaust survivor had reportedly been protected by wild dogs in the Siberian forest when she was a child.

#### ***Sub-theme 4: The physical environment***

The data highlight some aspects of the physical environment that can potentially cause distress for older survivors. Sensory stimuli, including sights, sounds, and particular smells, may be reminiscent of past traumatic experiences. Many examples of distress caused by an aspect of the physical environment in residential care facilities were mentioned by the interviewees. Family carers explained that enclosed spaces, including long corridors, windows that do not open, and locks on doors, can lead to feelings of lack of control or an inability to escape (see Table 8, Quote 9).

Shutting the door of the client's room (particularly at night) can raise anxiety about not being heard if they call out. A family carer felt that because some Holocaust survivors spent the whole war in hiding, it is important in residential care that the staff can hear them and that they will get a response when they need something. It was also mentioned that because of their past experiences, older survivors can be highly sensitive about staff entering their room without knocking (See Table 8, Quote 10).

Aspect of communal living that were seen as potentially distressing for Cambodian and Holocaust survivors alike were the lack of privacy, perceived loss of identity, communal dining, and hearing particular accents (spoken by both staff and other residents) that they associate with their former oppressors. In addition, older survivors may be exposed to hearing the crying or moaning of other residents (particularly in high-level care). One family carer felt that the Holocaust survivors who were in concentration camps and heard their relatives or friends dying would not be very tolerant of hearing the suffering of others in a residential care facility.

While the physical environment in residential care facilities was discussed more frequently than community aged care environments, a number of situations in community care settings were also reported. For example, a Home and Community Care (HACC) worker in Dandenong found out that her client of 18 years had been the victim of torture during WWII when he reacted to a dripping tap (see Quote 11).

**Table 8: Potential reminders of past trauma in the aged care environment**

<u>Sub-theme 1: The social environment</u>	
1	<i>One day myself and my colleague came to work accidentally dressed alike in a dark skirt and blouse and one lady became absolutely terrified. She ran to the gates and they were locked. She was screaming asking for help from passers-by because she thought that she was in the camp and that we were wearing uniforms .....she was screaming, she was so desperate to run away. [PAG Activities coordinator]</i>
<u>Sub-theme 2: Care or support tasks</u>	
2	<i>(In hospital when I went to the toilet) I asked for a woman because I really feel humiliated when a man has to come and help me in the toilet. So most of the time a woman came. But very often the men came. And they keep telling me 'you hate men do you?' And I said to them I didn't hate men but that I need some privacy ....I didn't explain this to them that in the camp ... we didn't have a toilet in the barracks. We went out in the open and on the other side of the barbed wire were men living. So it is most embarrassing for me. It wasn't a matter of hate. I didn't mind men for anything else but not in the toilet. [Holocaust survivor]</i>
3	<i>I remember that I had a shower (in hospital) and after the shower the nurse started to tell me to go out and without the towel. I was sitting for about 15 minutes naked and shivering, waiting to get dry. No help and no understanding. So this was the worst experience I had in the hospital which reminded me of (the camp) and I had something like that experienced only in Auschwitz. [Holocaust survivor]</i>
4	<i>...(My parents-in-law) never had a shower in all the years (since the war). They always took baths... For years we never sort of realised. We'd find that they had stuff put in to their shower recess that they were just using it like storage and then it twigged on us...(when she went to residential care)...she didn't want to shower, she kept saying I'm clean, I don't need a shower...and it was always difficult to get her into the shower. Apparently, she screamed through it. Being a Holocaust survivor for her a shower meant death. [Family carer]</i>
5	<i>With the confidentiality form we've had issues going out and asking them to sign but I had quite recently one gentleman who the following morning phoned me and had not slept during the night because he really had forgotten why he signed it and it really upset him and in the meantime he didn't know his wife had actually signed it. And then he was upset with her and so things need to be really clear [Case manager]</i>
6	<i>My mum was at the nursing home once... She wouldn't open her mouth to be fed and the person who nursed her would not force the food into her mouth, they don't see why they should have to force her...if they don't understand this is the way my mum eats. They would not do it and my mum of course would not be able to survive by not eating for so long...I felt responsible and I had to take her home. [Daughter of a Cambodian survivor]</i>
<u>Sub-theme 3: Involvement in planned activities</u>	
7	<i>He said 'I don't care about dentists anymore since I was in Auschwitz and lost all my teeth'. We knew that in future we had to protect him from this sort of discussion. So there's so much detail we should really know and understand about clients in order for them to feel comfortable and protected when they're with us. [PAG activities coordinator]</i>
8	<i>We had a religious festival, it was hell for me emotionally because she [older survivor] would go really angry...Imagine, when she was a young woman, there were 50 people at the table, at the Passover, where are they, it's emotional. I'm missing something very important that's gone you know. And the festivals bring it back and I think staff might have to keep in mind that festivals are triggers and people will either remember their family as being alive and being sad or they remember losing them you know. They're the trouble spots, the festivals. [Daughter of a Holocaust survivor]</i>
<u>Sub-theme 4: Aspects of the physical environment</u>	
9	<i>The fact that we can't open windows?... It's like a jail.' [Family carer]</i>

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|----|---|
| 10 | <i>It is like a reminder of people bursting into the house [during the Holocaust]. The reactions are stronger than they would be [with other residents]. It's that difference between annoyance to absolute fear or horror. [Holocaust trainer]</i>   |
| 11 | <i>One day he said, 'Oh my goodness please turn that tap off' and then he explained to me that he was from Ukraine and he was tortured. ... They put him at the bottom of some stairs... and they had a bucket with a hole in it and that was to drip on his head and that was just like an explosion when it landed on his head. And that's why he couldn't stand the dripping of the tap. It sort of brought back those memories. [HACC worker]</i> |

## **Section 4: Aged care workers' experiences of providing care for older survivors**

Aged care workers were asked about their experiences of working with older survivors and family carers. Five main themes emerged from the data.

1. Recognising clients who may be older survivors
2. Comprehending trauma experiences and responses
3. Encountering challenging situations
4. Feelings about working with older survivors
5. Developing effective carer-client relationships with older survivors

### **Theme 1: Recognising clients who may be older survivors**

The ways that aged care workers find out or do not find out about older survivor clients' backgrounds emerged as a key issue. While information about clients' life histories is routinely collected prior to admission to residential care and often taken into account by activities coordinators, focus group discussions suggested that this information is not often shared with personal care attendants. In community care, information about clients' life histories may emerge at the time of the assessment but the way this information is recorded or incorporated into care plans is entirely dependent on the organisation. The evidence showed that Jewish community services are very mindful of older clients who are survivors of the Holocaust and go to great lengths to accommodate their individual needs and preferences. Mainstream community service providers' use of information about clients' history of trauma is variable. In several focus group discussions HACC home help workers reported that when they visited a new client they rarely knew anything about their background and that they did not have access to this type of information. They sometimes found out about the clients' past informally from co-workers or supervisors and sometimes they learnt from the clients themselves as they started to know them better.

The data also showed that a lack of background knowledge can lead to disastrous consequences for both clients and workers. In one reported incident, a young personal care attendant noticed the concentration camp number tattooed on a Holocaust survivor's arm. Unaware of what this tattoo represented and the involuntary way that the resident (and all other concentration camp internees) had received it, she said to him, 'Oh that's a cool tattoo where did you get that from?' The Holocaust survivor was distressed by the question and so too was the young woman when she found out the answer to her question from the other staff. Focus group participants felt similar occurrences happened because aged care staff, in particular younger ones, often have little knowledge about events such as the Holocaust and the Cambodian genocide.

The data demonstrated that relevant knowledge and experience can assist aged care staff to consider the possibility that a client is an older survivor. For example, aged care workers who had worked extensively with Jewish clients stated that they can often work out if a client is a Holocaust survivor if they know the client's religion and country of birth and when they arrived in Australia. A Cambodian welfare worker pointed out that it could be assumed that 90% of older Cambodians living in Australia are survivors of the 'killing fields'.

The benefit of having relevant knowledge and experience for recognising a client with a trauma history emerged from the data. A former Jewish Care staff member related the experience of being called out one night to a mainstream nursing home to assist staff with a distressed resident who had

dementia. It emerged that the resident had never revealed to anyone that she was a Holocaust survivor. A staff member at the facility, who had previously worked at a Jewish dementia-specific facility, realised that the resident was a Holocaust survivor when she reverted to Yiddish (a European Jewish language) and became anxious when hearing someone speaking in Polish. In the second example, a Cambodian carer respite worker had been asked to help the home nursing service when they could not get into the home of an older Cambodian woman who had returned home from hospital after being hit by a car. The Cambodian worker had discovered that the client had become terrified of her neighbours' car headlights shining into her flat at night. This had triggered memories of the night time danger during the Pol Pot period when Khmer Rouge patrols would shine bright lights into homes when they took people away from their families to be killed. The client's response to the car headlights was to darken her flat and block her windows with furniture.

## **Theme 2: Comprehending trauma experiences and responses**

The predominant view among focus group participants was that aged care workers who have generalised knowledge about genocide history, trauma experiences and reactions and their long-term impacts are better able to understand the emotional state of older survivor clients and the ways that they may respond to various situations in aged care settings.

In some cases aged care workers can identify with older survivor clients through their own experiences of trauma. One residential care activities coordinator, who had experienced the political violence of the 1970s in Chile, was particularly attuned to the Holocaust survivor residents that she worked with. Sometimes a single object helped the aged care worker to comprehend the meaning of the genocide for their client. A HACC home help worker felt that he began to understand the meaning and the impact of the Holocaust for one of his clients when saw a pre-World War II photo of her family on her buffet and she explained that only two of the 20 family members in the photo had survived the Holocaust (see Table 9, Quote 1).

Overall, interviewees felt that knowing specific details of the clients' traumatic experiences was not necessary (see Table 9, Quote 2). At the same time, the data highlight how difficult it can be for aged care staff, especially those with little experience of working with this client group, to comprehend the life-long effects of genocide. Focus group participants' comments demonstrate that, in general, aged care workers who worked closely with older survivors and those who had developed client-carer relationships over a long period of time, were most likely to comprehend the enormity of individual survivors' tragedies.

A CACP case manager who at the time of the research was working at Jewish Care felt that many carers who encountered Holocaust survivors in mainstream services did not understand 'where their anxiety comes from' (see Table 9, Quote 3). As a case manager who was working closely with Holocaust survivors and their families at the time of the research, she felt that she developed a deeper understanding of how the Holocaust continued to affect some of her clients. She believed that Holocaust survivors were not anxious by nature. She has attempted to explain to her colleagues that the anxiety is there for a reason. Similarly, a Cambodian activities coordinator felt some of the older Cambodian people who attend her PAG expressed grief through anger, which was sometimes directed at the staff. A number of family carers suggested that older survivors in residential care who were perceived to be 'difficult' or 'demanding' by aged care staff were more likely to be ignored than other residents. One family carer related the situation of an older survivor with dementia who cried constantly and was ignored by the staff (see Table 9, Quote 4).

Findings indicate that aggression or other behaviours perceived to be ‘difficult’ by care providers sometimes occur in response to something or someone in the environment that is causing the older survivor to feel anxious, fearful or unsafe.

**Table 9: Comprehending trauma experiences and responses**

1	<i>One lady that I used to go to ... one photo appeared on her buffet and it was about 20 people and she went through the people .... that's my father, that's my mother, that's my three sisters, that's my two brothers, that's my aunty. And I am sitting there going, 'Oh yeah that's lovely. What a lovely photo'. And then she said 'they are all dead except for these two'. I remember after that every time I went there to work and clean I looked at that photo, I just thought – it made it really real for me, that there's this photo. Where if you just hear of it and then you see this photo and if you know this lady and that's her whole family all gone. [Council home care worker]</i>
2	<i>Understand the total experience in general, the herding that they had, the idea of public showers and being naked in front of them [camp guards], all of that, what it means...If you understand in a daily sense what these people went through, it gives you a general idea – you don't have to know the specific. [Case manager]</i>
3	<i>I used to work at Caulfield Hospital as a nurse and I go back to visit my clients when they are there sometimes, so I know the girls, and one of the things they often say to me is, they don't understand where the anxiety comes from. They don't get it. They know they are Holocaust survivors, but they don't get it and I am pretty sure I was always sensitive to that but I've got a greater appreciation and understanding of it now working in here. But they honestly don't get the anxiety. I think that is really important to the carers to understand where the anxiety comes from and why they do it. They are not anxious because it is inherent in their nature, there's a damn good reason for it, you know, 'I lost everybody in my world' or 'I lived for four years without hardly any food' et cetera. I think there is anxiety about what could happen in the future, the fear they might lose it all again. [CACP Case manager]</i>
4	<i>A lot of them [residents] that call out and they're totally ignored...I guess these people do yell out all the time, but they just take no notice of them. When a person is calling out continually, obviously there's something that's bothering them, I mean there used to be one lady there that used to burst out crying at the drop of a hat, but apparently she was Russian and when they spoke to her in Russian, they learnt that she was asking for her brothers and sisters, mother. She was getting upset because they weren't coming. All she really needed was someone to come and say 'it's okay, they're alright don't worry about them', because you can't turn around and say they're gone, that doesn't register.</i>

### **Theme 3: Encountering challenging situations**

Focus group participants were asked about whether they had encountered any difficulties when providing care for older survivors. Four sub-themes emerged from the analysis of their responses.

#### ***Sub-theme 1: Exposure to ‘challenging’ behaviours***

Some focus group participants described being exposed to behaviours that they perceived to be ‘challenging’. The quotes in Table 10 illustrate instances when older survivor clients were described as ‘aggressive’ (Quote 1), ‘unpleasant’ and ‘non-cooperative’ (Quotes 2 and 3), ‘nasty’ (Quote 4), ‘difficult’ (Quote 5) and ‘suspicious’ (Quote 6).

***Sub-theme 2: Exposure to extreme grief***

Many focus group participants had found that older survivor clients usually avoid talking about the past. Some workers, however, described occasions when they were exposed to older survivors' expressions of tremendous grief. Often these older survivors were clients or residents with dementia. A Vietnamese HACC worker had provided personal care for a Chinese–Cambodian client with dementia. The client cried a lot because she had been separated from two of her daughters during the Pol Pot period and had never heard from them again. An agency aged care worker spoke of working with two Holocaust survivor residents who cried all day. She claimed that they never stopped crying even when they were being fed. The participants unanimously agreed that they found these situations very upsetting.

Focus group participants also spoke about situations when asking the client about their family had provoked grief. An ACAS clinician related her experience of an assessment with a Vietnamese client who burst into tears when she spoke about her nine children. Two had been slaughtered in Vietnam and five died on a boat on the way to Australia. Other interviewees described older survivors' angry or aggressive behaviour towards aged care staff as the clients' way of expressing grief (see Table 10, Quote 7).

***Sub-theme 3: Clients experiencing extreme fear***

A number of focus group participants had unwittingly caused extreme fear reactions from older survivor clients which they had not been able to anticipate. In these situations, the aged care workers found out after the event that their actions had reminded clients of some aspect of their traumatic past (See Table 10, Quotes 8 and 9). A personal care attendant (PCA) working in a residential care facility encountered a Holocaust survivor with dementia who became distraught when she brought him a meal. Staff members were able to find out that he felt that he was in prison and was not going to get another meal. The depth of the client's distress had been extremely confronting for the PCA (see Table 10, Quote 10).

***Sub-theme 4: Fluctuating actions***

Focus group participants spoke of fluctuations in some older survivors' moods and behaviours (see Table 10, Quote 11). Several aged care workers, for example, described their frustration when they had put a lot of effort into setting up a service or an outing for an older survivor client who subsequently changed their mind and withdrew (see Table 10, Quote 12). In addition, an activity that may not usually cause any distress for a client may for some reason unbeknown to the worker become a problem for the client on a particular day. An example of this situation was the experience of a PCA who showered a Holocaust survivor every day, but one day when she was helping him into the shower he 'flipped out' and bit her. Later when he calmed down he apologised and explained that it was to do with the gas chambers.

**Table 10: Aged care workers' experiences of providing care for older survivors**

<u>Sub-theme 1: Exposure to 'challenging' behaviours</u>	
1	<i>I've had residents punching, hiding pills and I've been attacked with a butter knife. Some of them will play up just because they are in the mood. But I find the ones who don't speak English are most difficult and being a male makes it even harder. [Division 1 Nurse, residential care]</i>
2	<i>Some of them [the Holocaust survivors] are very unpleasant. And it is very difficult to make them do things. One time a lady said 'stop telling me what to do we are not in a concentration camp'. [Agency PCA]</i>
3	<i>It's very difficult to make them do things. They want to do things their own way. [Agency PCA]</i>
4	<i>One lady, when I was doing the recreation course and my assignment was to write about a difficult client and this lady was difficult. She was bossy, she was nasty to everybody, there was no way you could talk to her. Eventually, she said to me, 'You think I'm really hard, don't you? ...I've been through a lot. I don't cry, I don't let anyone see me crying because it's not their problem it's mine, and I've to keep holding myself up'. So she would keep it in and she was just nasty to everybody. But as she talked more and more it came out. [PAG physiotherapist]</i>
5	<i>A client can be really difficult and then after a month or so you find they start to relax and talk more. And you think 'gee, they're totally different and I feel sorry maybe I judged them wrong'. [Focus group participant]</i>
6	<i>One lady was meticulously clean and she just followed me around while I was cleaning. You know I would turn around and she would be right there. I talked to her as I cleaned and as I found out more about her I understood more. In the end she didn't do it as much because she knew that I did a good job. [HACC, Home Help]</i>
<u>Sub-theme 2: Exposure to extreme grief</u>	
7	<i>I often see outbursts of anger or sudden grief. Some people hide their grief inside. They seem happy but inside they are crying. Many are angry with their children because of the lack of emotional and other support. Sometimes they shout at me instead of at their children. I just accept it and move on. I often change the subject. Everybody in the group lost their husband and some of their children. The pain is still there and they are very emotional. [Activities coordinator, Cambodian PAG]</i>
<u>Sub-theme 3: Clients experiencing extreme fear</u>	
8	<i>Clients don't often tell you (that they are survivors). I mean you find out usually when it's too late. Because I used to walk a client and she like to go out and walk. One day she stepped out on her own. I pulled her back like that and she went hysterical and she was hitting me 'Don't touch me, stay away'. When I got back in I talked about it to someone who used to work here...It turned out the guards used to touch on the shoulder the women they wanted.....You don't know about it. That affected her for a good month before she would actually speak to me. [PAG staff member]</i>
9	<i>I've only had one negative experience with someone in touching them – it's a routine part of physio if someone has a stiff joint to want to make it move and I remember doing some passive movements and putting her hand up and she got quite agitated and left quite angry. She actually she had the insight to come back the next week and tell me that she had been held down as a small child and had her appendix removed without an anaesthetic during the Holocaust. She couldn't handle that feeling of being in an open position and being vulnerable. [Physiotherapist at a Jewish PAG]</i>
10	<i>(Working in residential care) one night I took a food trolley up to a resident who was new and he was crying and I took the tray and as I was going out he said to me, 'How long do I have this for?' I just didn't know what he meant. I didn't realise until I walked away that he thought that I wasn't going to come back with any food another day. He just sat and cried until we got</i>

somebody to go and see him. He thought that room was his prison and he was only going to get that food and he wasn't going to get anymore. I've never seen a man so upset. He was really crying.... You don't know that when you go in a room...nothing prepares you. You just don't know what to say to stop it. It's very hard.' [PCA, Residential Care Facility]

#### Sub-theme 4: Fluctuating actions and decisions

11 [A client of mine has recently] realised that she has two separate identities – the child from the Holocaust with all those fears and then after she came out here .....the adult who just had to be busy and carry things through. This can shift [from one identity to the other] in one second. So she herself is becoming aware of that and she is starting to manage that. She admits she can respond to carers [providing care in her home] very poorly and that's an issue for her and if they touch her where she thinks it is inappropriate or they say something that she perceives as something that is a threat to her she can respond very poorly to that.[Clinician, Planned Activity Group]

12 I assessed a Holocaust survivor who was taken from her family at the age of 12. She said there has been a sort of black cloud hanging over her head since. She suffers anxiety and depression and nightmares. She's a difficult lady to help. She tells you all these terribly sad stories, you just come out weeping but then after the referral I had made she changed her mind because there was something else on that day. [ACAS clinician]

### Theme 4: Feelings about working with older survivors

Aged care workers expressed a range of feelings about working with older survivors. These feelings have been categorised into four sub-themes outlined below.

#### *Sub-theme 1: Empathy and fulfilment*

Some aged care workers expressed great empathy for older survivor clients and admiration for the clients' life achievements despite their traumatic wartime experiences. Some aged care workers spoke of their feelings of personal fulfilment when they succeeded in getting services into an older survivor's home or when they were able to help reduce their social isolation (see Table 11, Quote 1).

Others felt privileged that some older survivors had chosen to share their life stories with them. The focus group evidence suggested that aged care workers who feel great empathy towards older survivor clients were extra-sensitive about the way they provided care. For example, a case manager took extra care to be reliable and to 'stick to her word' and an activities coordinator in a Jewish residential care facility took steps to protect the client's dignity (see Table 10, Quote 2).

#### *Sub-theme 2: Sadness about the suffering older survivors have endured*

Some aged care worker interviewees expressed sadness about the suffering that older survivors had endured (see Table 11, Quote 3). One PCA revealed that she became very sad and uncomfortable when the Holocaust survivor residents told her about how they were treated during the Holocaust but she tried not to show them how she felt (see Table 11, Quote 4).

#### *Sub-theme 3: Ambivalence*

The literature suggests that some workers may be reluctant to be exposed to potentially overwhelming emotions associated with their clients' prior trauma. They may react by distancing themselves from people who are victims (Kaplan, 1998). Some evidence of this type of reaction also emerged from this research (see Table 11, Quote 5).

**Sub-theme 4: Intolerance**

Some project participants spoke about working with staff who thought that older survivors should move on and forget the traumatic things that happened to them in the past. Some focus group participants had found some older survivors’ behaviours to be irritating; in particular, behaviours relating to food. One PCA mentioned being annoyed by an older survivor who refused to stop taking extra food and giving it to a friend who was not living in the facility.

**Table 11: Feelings about working with older survivors**

<u>Sub-theme 1: Empathy and fulfillment</u>	
1	<i>You see their whole lives open up when they come into the centre [PAG]. From being isolated at home and we go out to some of the assessments and not seeing anyone from week to week and then suddenly they come here and after joining a couple of groups you just see them flowering and participating. It’s just amazingly beautiful to see. [PAG activities coordinator]</i>
2	<i>A lot of times, I stop them (agency worker) in the corridor when they take the resident from the room to the shower with a nappy and a chair. I haven’t got the right to tell them, but I make it my right. I say, ‘excuse me sweetheart, would you take your father or mother like this?’ Hello, wake up, pick up a dressing gown and put it on them [Activities coordinator, Residential Care]</i>
<u>Sub-theme 2: Sadness about the suffering older survivors have endured</u>	
3	<i>[In the first month when I started working in Montefiore Home 20 years ago] I came home and I started crying.... Still sometimes I say it is hard to accept that all these people suffered so much and you can’t do anything because this has already passed. [Activities coordinator]</i>
4	<i>I take a deep breath and I continue and I don’t let them know that it affects me but it does affect me but I can’t let them know. [Personal care attendant]</i>
<u>Sub-theme 3: Ambivalence</u>	
5	<i>I’ve formed a very distant relationship with one older Cambodian man. He’s very guarded about what he talks about but he did talk to me once about what happened to him [in Cambodia]. I was like ‘oh my god’ but I didn’t say that to him, I said, ‘It must have been really hard for you’, and I changed the subject. [PAG activities coordinator]</i>

**Theme 5: Developing effective carer–client relationships**

Developing effective carer–client relationships is a pivotal principle of person-centred care. The focus group discussions and interviews with key experts enabled researchers to identify the range of strategies that aged care workers had used to develop effective working relationships with older survivor clients. These strategies were categorised into four sub-themes:

**Sub-theme 1: Remembering what the client has been through**

Being conscious of what older survivor clients may have been through helped aged care workers to put challenging situations into perspective. Focus groups participants felt that having an understanding of the clients’ past could also help them understand anxious, suspicious, aggressive or fluctuating behaviour. One aged care worker explained that, even though some of the older survivors behaved in ways that could be really upsetting, she did not react and eventually, when they felt more secure, they stopped behaving in that way (see Quote 1, Table 12). The evidence illustrated that remembering what the client had been through could assist aged care workers to understand what

clients were telling them (see Quote 2, Table 12) and to be patient and non-judgmental about what older survivors said and did.

***Sub-theme 2: Understanding how to talk to clients about their past***

The data showed that it is important for aged care workers to understand how to talk to older survivors about the past and indicated that aged care workers should:

1. Be informed about past events to avoid inadvertently asking insensitive questions
2. Avoid asking probing questions about past trauma
3. Be willing to listen if the client wishes to talk about the past (see Quote 3, Table 12)
4. Be able to respond appropriately to older survivors who wish to talk about their past traumatic experiences (e.g. showing that they believe what the clients are telling them).

***Sub-theme 3: Building trust***

Building trust was seen as the key to developing effective working relationships with older survivor clients (see Quote 4). Frequent rotation of home help workers (in the clients' homes) and personal care attendants (in residential care), which results in short periods of contact between workers and clients, was considered particularly detrimental for older survivors, whose ability to trust others may have been severely damaged by their genocide experiences. Being reliable was seen as a major way to gain older survivor clients' trust. A case manager had said that she set up initial trust by 'sticking to her word'. She made sure that she did what she had said she would do without delay.

Another important element in building trust was thought to be communicating information clearly. Focus group participants suggested that with older survivors it was especially important to make sure they understood what was going to happen before it happened. This was considered particularly important in relation to personal care. Another example of the importance of communicating information clearly was that of signing official paperwork. Care coordinators suggested that this could cause intense anxiety for some older survivors (due to a deep distrust of government and government officials) and that extra care should be taken to make sure that older survivor clients understand what they are signing.

The evidence showed that aged care workers could help older survivor clients feel 'comfortable' and 'protected' by being flexible in the way they ran an activity or how they completed a task. Adopting a flexible approach involved listening to clients or paying attention to their sensitivities and fears and adjusting activities accordingly. This approach is illustrated in Quote 5. Other trust-building strategies used by aged care workers included:

Conveying knowledge of clients' cultural background (language, customs, religion and history)

1. Ensuring that clients felt physically comfortable and safe
2. Showing warmth, a caring attitude and interest in the client
3. Sharing information about themselves with the client
4. Using humour.

***Sub-theme 4: Responding to challenging situations***

Focus group participants spoke of a range of strategies for responding to challenging situations. Examination of the data revealed that experienced aged care workers were often able to identify the factor(s) in the social or physical environment that were causing individual clients to feel anxious or fearful. Awareness of the clients' past, flexibility, and a person-centred approach were key to responding effectively. Some aged care workers did not react directly to the client's 'behaviour' rather they reacted to the 'person'. These were generally workers who felt that they understood 'where the behaviour was coming from' so instead of responding to behaviours such as verbal aggression or distrust, they used diversion techniques such as humour, changing the subject, or proving themselves as trustworthy by simply doing a good job (see Quotes 6 and 7, Table 10). Focus group participants pointed out that this strategy was useful only if the challenging behaviour posed no threat to the safety of the client or the worker. Other person-centred strategies employed by some workers were prioritising the experience of the individual person rather than completing the task at hand, and formulating individualised strategies ensure that the older survivor client felt safe. For example, an activities coordinator avoided discussions about visits to the dentist because she knew that it caused distress for a particular client who had had a brutal wartime experience (see Quote 6, Table 12).

Some aged care workers had experienced situations in which they had been unable to anticipate clients' fear responses to aspects in the social or the physical environment that had been perceived to be threatening. Some had been greatly assisted by being able to consult with an informed and experienced supervisor or other staff member (see Quote 8, Table 10).

**Table 12: Developing effective carer–client relationships**

<u>Sub-theme 1: Remembering what the client has been through</u>	
1	<i>You've got to remember what they've been through. Some of them can upset you and can be really nasty and then you've just got to think and not react to it, and eventually it does go away.....They come round in the end. Although they know they're wrong they don't apologise but they're so nice that you just forget it. [HACC worker]</i>
2	<i>You've got to be very open to hearing more than they say. You've got to be really open. Sometimes they'll tell you a lot but they're not telling you significant stuff like the care they actually need or that they're not managing at home because if you're sick and frail then in terms of the Holocaust those were the ones who would be killed so they hold back on some stuff and tell you a lot of other stuff. [CACP case manager]</i>
<u>Sub-theme 2: Understanding how to talk about the client's history of trauma</u>	
3	<i>When working with survivors, you have to recognise the special moment when you have to put everything aside and sit back and listen ... and then things fall into place. [HACC worker]</i>
<u>Sub-theme 3: Building trust</u>	
4	<i>And I think it is the survivor of any trauma that the issue about trust will be much harder, fundamentally broken and it can never really be healed. So when somebody says I'll be back in a minute and they don't come for two hours it is major, major, it's not just an annoyance it's like ...I can't rely on anybody. [CACP case manager]</i>
5	<i>I have tried to say to my mates [at Caulfield Hospital], 'look you need to acknowledge the anxiety and there are ways, give them what they want when they want it. And you have to be more patient and sometimes you have to sit down for five minutes and listen to them'. There are ways of working with them. A lot of people who don't understand, and will probably just be quite resentful and go the opposite direction, go the other way. [CACP case manager]</i>
<u>Sub-theme 4: Responding to challenging situations</u>	
6	<i>We had a client we knew not to speak about dentists in his presence because when somebody around the table mentioned a dentist appointment and he became so, so upset, he was so distressed ...and said 'I don't care about dentists anymore since I was in Auschwitz and lost all my teeth'. We knew that in future we had to protect him from this sort of discussion. So there's so much detail we should really know and understand about clients in order for them to feel comfortable and protected when they're with us. [Jewish PAG activities coordinator]</i>

## Chapter 4: Discussion

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As the population ages and people live with more years of disability, community and residential aged care staff in Australia will be caring for many more people who have experienced traumatic life events. Survivors of genocide are victims of arguably the most extreme form of trauma. This research highlighted the importance of recognising older survivors of genocide and mass trauma as a distinct group of aged care clients and recognising training of staff for caring for this client group as distinct from cultural competency training in aged care. The evidence presented in Chapter 3 has contributed to our understanding of how traumatic experiences influence interactions between older survivors and aged care workers, and how aged care workers can contribute to the provision of optimum aged care for older survivor clients.

This study supported the view of trauma and ageing which suggests that the sequelae of extreme trauma should be understood jointly in terms of vulnerability and resilience (Shmotkin, 2003). The Holocaust survivors and older Cambodian survivors who participated in this research had typically endured extreme and prolonged trauma, and suffered multiple losses, multiple relocations and economic hardship both during and after the period of traumatisation. After resettling in Australia most had led productive and active lives but simultaneously experienced some of the long-term psychological and psychosocial effects of the earlier-life trauma. Some interviewees continued to suffer from the physical impacts of their earlier-life traumatic experiences. Many older survivor interviewees had experienced worsening of intrusive memories, nightmares and sleep disturbances and other trauma symptoms which they attributed to changes in their lives brought about by the transitions of ageing. They felt that increasing frailty or slowing down from previously busy lives had precipitated more frequent and intense feelings of grief and loss, and the feeling that traumatic memories were ‘catching up with them’. Family carers—many of whom were the children of older survivors with dementia—also reported that their parents struggled with traumatic memories.

In-depth interviews helped shed light on older survivors’ experiences of receiving aged care services. As for other older people, the receipt of aged care services is often accompanied by feelings of loss; however, for older survivors, increasing dependency on others for their everyday needs can be an unpleasant reminder of an earlier time when control over their lives was stripped away by force. Traumatic earlier-life events were found to impact on older survivors’ ways of coping with the aged care environment. For some older survivor clients, the feeling of increasing dependency can exacerbate post-traumatic stress symptoms, particularly when the care is being provided by a non-family member. Feelings of powerlessness in aged care settings can also reactivate behaviours that were essential to survival during the period of traumatisation such as hoarding, suspicion of strangers, and social withdrawal. The research also found that older survivors may be exposed to reminders of past traumatic experiences in both community and residential aged care environments. These reminders can occur in the social environment, the physical environment, or they may be activated by particular care-giving activities or participation in planned activities. Any aspect of an aged care setting can act as a reminder of traumatic experiences because every individual survivor had their own unique trauma experience. Not even the client is always aware of the impact that a specific reminder may have on them until after the event. As a result, older survivor clients’ behaviours can be difficult to anticipate.

Specific aspects of the physical environment that can create difficulties for older survivor clients include living in close proximity of other people and concern about insufficient or unsuitable food (see Table 8, page 33). With respect to the social environment, the evidence indicated that interactions with aged care workers generally results in expected care outcomes such as meeting the clients’

activities of daily living needs. Older survivor interviewees receiving home care services also identified the contribution that warm, trusting and reliable relationships with home help workers made to their sense of security and social connectedness. Participation in planned activities (both in residential care and at Planned Activity Groups) was found to have great benefits for older survivors. This was particularly true when activities coordinators were conscious of the traumatic past of some or all of the participants and they integrated this information into the way that they ran activities. The benefits that were described by older survivors included opportunities for meaningful activities, social interaction, and physical activity. Many of the older survivors (both Holocaust survivors and older Cambodian survivors) felt that these activities helped them cope with the long-term psychosocial impacts of past traumatic experiences. Some suggested that activities such as discussion, art, and writing had provided them with a 'safe' way to confront traumas of the past (see Table 7, page 29).

Problematic aspects of the social environment included frequent turnover of staff; the physical attributes of some staff (or other clients) such as physical appearance or accent; and the way some staff communicated with older survivor clients. In situations where older survivors perceived an aged care worker to be threatening their safety or failing to respect their dignity or privacy, client responses ranged from extreme anger to complete withdrawal. Older survivors were more likely to respond with actions such as physical aggression or social withdrawal than with words, even when language was not a barrier to communication (see Table 10, Quotes 6, 8 and 9). An older survivor who had explained to her carer how she felt about being assisted in the toilet by a man reported that her request for female assistance was resentfully shrugged off by the male carer (see Table 8, Quote 2).

Analysis of staff perspectives on the care of older survivors revealed that, as in previous research (outlined in Chapter 1) aged care and nursing staff sometimes encounter difficulty providing care for older survivors. The study found that provision of aged care for older survivors could be negatively impacted by signs and symptoms of post-traumatic stress. Older survivors who demonstrated heightened sensitivity to the way care was provided, and coping mechanisms such as mistrust, suspicion, and aggression tended to be described as 'difficult', 'anxious' and 'paranoid'. Older survivors' emotions were sometimes perceived to be exaggerated and in a few instances 'challenging behaviours' were viewed as deliberate or calculated to annoy the care provider. Aged care workers who knew little about the older survivor client's history or did not comprehend the potential impact of that history, were most likely use such labels. Family carers suggested that older survivors who were perceived by staff to be 'likeable', 'resilient', 'warm', or 'compliant' were more likely to be treated 'kindly' and to have their physical needs met in a timely manner than the 'hard work' older survivor clients.

Need-driven behaviours (NDBs) is a construct described by Algase et al. (1996) for understanding the behaviours of people with dementia. The authors proposed that 'although disruptive from an objective stance, NDBs constitute the most integrated and meaningful response possible, given limitations imposed by dementia, strengths preserved from the person's basic abilities and personality and constraints, challenges, or supports offered by the immediate environment'. This is a useful construct for understanding older survivors' responses to reminders of past trauma in the physical or social environment in aged care.

Aged care workers who were aware of older survivor clients' life histories, valued these clients, and treated them as individuals, showed greater understanding of what older survivors clients said, what they did, and how they reacted to the people and activities around them (see Table 9, page 37). These aged care workers established effective communication and trusting relationships with older survivors. Analysis of data revealed that they achieved this by grafting trauma-sensitive and person-

centred processes onto their established trauma-related knowledge and attitudes. The outcome of this approach was that they were usually able to complete aged care tasks in ways that did not cause distress to the client. The wide range of person-centred processes that emerged from the research is reported in Chapter 3 (e.g., prioritising the experience of the person rather than completing the task at hand, incorporating biographical knowledge into care plans). A further issue to emerge from the research was the difficulty some staff faced in coping with their own feelings of sadness when working with older survivors.

The key construct to emerge from the findings is an approach to care for older survivors that will be referred to as ‘trauma-sensitive, person-centred care’. This is an adaptation of Brooker’s (Brooker, 2007) model of person-centred care. The TS\_PCC approach involves the aged care worker having general knowledge about the impact of trauma on older survivors’ lives, access to relevant information about the life experiences of older survivor clients; trauma-sensitive attitudes (including recognition of older survivor clients as a distinct group of individuals in aged care; valuing older survivor clients, and looking at the aged care environment from the older survivor client’s perspective); and knowledge of a range of person-centred and trauma-sensitive strategies for developing effective carer–client relationships. The range of strategies can be conceptualised as a toolkit from which to choose the strategy that best suit the situation). TS\_PCC approach is the key theoretical construct around which a future staff training program will be based.

In keeping with McCormack and McCance’s (2006) framework for person-centre care, this study recognises that training staff in ‘trauma-sensitive, person-centred care’ is only one component in the delivery of optimum aged care for older survivors. The attributes of aged care workers and the care environment which denotes the context in which care is delivered are also integral components of this care. In aged care there can be substantial barriers to changing the way care is provided such as high staff turnover, lack of resources, lack of support for change, and an entrenched task-oriented rather than person-centred approach to care. Achieving optimum care for older survivors requires an organisational culture that tries to ensure that the organisation’s policies, values, and service delivery approach practically support aged care workers in the delivery of ‘trauma-sensitive, person centre care’ for older survivor clients.

## **Conclusion**

Unlike prior research which focused on the views of paid carers (Adams, et al., 1994; Ehrlich, 2004; Levine, 2001), this research included the perspectives of older survivors and family carers. The importance of aged care organisations recognising older survivors of genocide and mass trauma as a distinct client group in aged care, and providing opportunities for staff training, was highlighted. Emerging findings supported the literature which shows that effective interactions and communication with older survivor clients requires aged care staff to have an understanding of traumatic life experiences and their long-term impacts. Finally, this qualitative research project identified the ‘trauma-sensitive, person-centred care’ approach of providing aged care for older survivors and the knowledge, attitudes and skills that underpin this construct. The next chapter uses the research findings to outline a model for training for aged care workers on caring for older survivors.

## Chapter 5: An evidence-based staff training model

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The staff training model provides a theoretical structure around which to build the Caring for Older Survivors in Aged Care training package. Based on project findings, the model proposes that training should:

1. Develop participants' understanding of the factual, conceptual and practice information that underpins the key concept 'trauma-sensitive, person-centred care' (TS\_PCC).
2. Promote participants' trauma-sensitive attitudes.
3. Assist participants to integrate new learning and attitudes with existing aged care knowledge.
4. Develop participants' ability to use problem solving to apply TS\_PCC in practice.
5. Reinforce participants' learning and support them to adopt the TS\_PCC approach in practice.

**Description:** The training will deal with working effectively with clients from torture and trauma backgrounds in aged care. It will focus on assisting aged care staff to learn about and implement the 'trauma-sensitive, person-centred care' approach.

### **Training outcomes**

#### *Immediate outcomes*

1. Improved understanding of factual, conceptual and practical information that underpins the key concept 'trauma-sensitive, person-centred care'.
2. Development of trauma-sensitive attitudes.

#### *Intermediate outcome*

Improved use of the TS\_PCC approach in practice.

#### *Long-term outcomes*

1. Improved aged care outcomes for older survivor client (such as client satisfaction with care, involvement with care, feeling of wellbeing; therapeutic outcomes).
2. Improved outcomes for aged care worker (such as job satisfaction).

**Essential knowledge**

Area of knowledge	Knowledge criteria
<b>Torture and trauma</b>	<p>Understanding of the meaning of genocide, mass trauma, and torture.</p> <p>Knowledge of the current profile of older survivors in Australia.</p> <p>Knowledge of diversity in older survivors' backgrounds and experiences.</p> <p>Understanding of the core components of the trauma reaction.</p>
<b>The long-term consequences of torture and trauma</b>	<p>Recognition that the consequences of extreme trauma are long-lasting.</p> <p>Understanding of intergenerational transference of trauma.</p> <p>Recognition of diversity in the ways that older survivors respond to past experiences.</p>
<b>Ageing and trauma</b>	<p>Recognition of diversity in the psychological wellbeing of older survivors.</p> <p>Recognition vulnerability and resilience in old age among older survivors.</p> <p>Recognition that older survivors may experience everyday situations, objects, places or sensory stimulus as painful reminders of the past.</p> <p>Recognition that the transitions of later life can contribute to worsening of post-traumatic stress symptoms.</p>
<b>The experience of aged care from the perspective of the older survivor client</b>	<p>Recognition of older survivors as a distinct client group in aged care.</p> <p>Understanding that as a result of traumatic experiences older survivor clients may be anxious about the way they are treated in aged care.</p> <p>Recognition of earlier-life trauma experiences as a potential factor in the behaviour of older survivor aged care clients.</p> <p>Knowledge of the elements in the aged care environment that may act as reminders of past traumatic experiences or cause emotional distress.</p> <p>Knowledge about the signs of anxiety, fear, anger, humiliation or powerlessness.</p>
<b>Trauma-sensitive, person-centred care</b>	<p>Knowledge of a range of strategies for building trust. Accepting expressions of emotion, being reliable, maximising clients' control over their care, setting limits, active listening, understanding how to talk about past trauma, gender sensitivity, respecting confidentiality, conveying knowledge of clients' culture and history, showing warmth and interest in the client, being flexible, communicating information clearly, using humour, treating complaints seriously, negotiating, sharing decision-making.</p> <p>Knowledge of strategies for responding to sign of distress. Removing the client from the cause of distress, and calming the client.</p>

## Essential skills

Essential skills	Performance criteria
<b>Communicating and interacting effectively with older survivor clients</b>	Demonstrate awareness of trauma as factor in the behaviour and responses of older survivor clients. Demonstrate the ability to take account of the need to promote trust, respect, and interpersonal connection. Ability to use a range of trauma-sensitive, person-centred communication strategies.
<b>Employing basic person-centred care skills</b>	Ability to recognise older clients who may be trauma survivors. Establish individual care plans that aim to ensure that the clients feel physically comfortable and safe. Establish individual care plans that recognise factors in the physical or social environment that may cause distress.
<b>Responding in a timely way to distress</b>	Demonstrate consideration of trauma-related issues if needs-based behaviours occur. Ability to identify factors in the physical or social environment that may cause distress for older survivors. Ability to establish individual care plans that aim to ensure the clients feel physically comfortable and safe. Ability to use problem-solving to respond in a timely way to signs of fear, depression, anger, distrust, and humiliation.
<b>Self-help strategies for staff</b>	Recognise when and how to seek assistance for oneself.

## Mode of delivery

The training sessions are to be delivered in an interactive, face-to-face format with a focus on discussion and problem-based learning activities. It is recommended that training be delivered by training professionals with backgrounds in counselling or psychology. Such qualifications are desirable because of the sensitive nature of some the material covered in the training and the potential for some training participants to have experienced some form of trauma in their own lives in the past.

## Next stage

The next stage of the project involves:

1. Developing comprehensive training and resource manual to provide all levels of staff who are involved in the provision aged care services with the background information they need to recognise, relate to and provide aged care for older survivors. The manual will also provide materials for trainers. An outline of the manual is provided in Appendix 1.
2. Developing and testing a staff training package.
3. Rolling out the staff training package.
4. Evaluating the effectiveness of the staff training package in achieving its stated objectives.

# Appendices

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## Appendix 1: Outline of the training and resource manual

The training and resources manual includes five main sections:

### 1. Materials for trainers

- A review of the relevant literature and theoretical models on trauma and ageing, and person-centred care
- Profiles of the migrant and refugee communities in Victoria by aged group and region
- Brief background information on historical events
- Training materials – including formal presentation of materials, discussion topics, role plays, audio-visual materials, and problem-solving and interpretative thinking activities using evidence-based scenarios and case studies from the research
- Assessment and evaluation tasks
- Instructions for delivering for the training content and assessment tasks.

### 2. Materials for training participants

A set of training information sheets suitable for staff with Certificate III or IV Aged Care qualifications and at a level of English that would take into account the English proficiency of staff from non-English speaking backgrounds. The topics include:

- Who are the survivors of genocide and mass trauma?
- What did they experience? (Emphasis on diversity of experiences)
- What are the long term impacts? (Emphasis on diversity of responses)
- What is it like for older survivors to receive care and support services at home?
- What is it like for older survivors to live in a residential aged care facility?
- How can I recognise aged care clients who are survivors of genocide and mass trauma?
- How can I help to make the experience of using aged care services better for older survivors?
- What can I do to improve my experience of providing aged care services for older survivors?

### 3. Profession-specific practice guidelines

- Service manager guidelines include providing staff training and support; developing relationships with external agencies (to enable referral of clients who are recognised as requiring additional assistance such as counselling, financial or housing support)
- Direct care worker guidelines include providing personal care and food-related situations
- Activities coordinators' guidelines include ways to promote social participation
- Aged care assessor, case manager and supervisor guidelines include: care planning, working with family members, interviewing clients, assigning direct care workers to clients, supporting direct care staff, and referring clients for counselling.

### 4. List of support services for older people from refugee backgrounds.

### 5. Useful resources (including relevant films, books, internet resources).

## Appendix 2: Data collection

### 1. Organisations involved in community consultations

1. Ethnic Community Councils of Victoria
2. South Eastern Migrant Resource Centre
3. Spectrum Migrant Resource Centre
4. Action on Disabilities with Ethnic Communities
5. Royal District Nursing Service
6. Jewish Care Inc., Victoria
7. Cambodian Association of Victoria
8. Cambodian Welfare Association
9. Cambodian Australian Welfare Council of NSW
10. City of Greater Dandenong council services
11. City of Port Phillip council services

### 2. Interview guides

#### *Questions for HACC clients/family carers*

1. Can you tell me about when and how you/your relative came to Australia?
2. Are you/is your relative receiving any help from family members with activities like shopping, cooking and cleaning?
3. Are you/is your relative receiving any help from family members with personal care?
4. Have you/has your relative ever received any home help or personal care from the council or any other people outside of your family?
5. Thinking about the different aged care workers that have been sent by (*name of the agency*) to help you, was there anything that you particularly liked about the way they provide care?
6. Was there anything that didn't work very well for you/for your relative?
7. Have you/has your relative had an aged care assessment (ACAS, HACC or other) to determine what kind of services you need? How did you/how did your relative feel about having this assessment?
8. Do you find that memories from the past bother you/your relative more now than they did when you were younger?
9. Have you found that there are situations, objects or events that can make the memories worse for you/your relative? Can you tell me about that?
10. Do you think it is important for home help workers or other aged care workers (*like the people who run planned activity groups*) to know something about what happened to the Cambodian people during the Pol Pot regime/Jewish people in the Holocaust? Why?
11. Do you/your relative participate in any planned activity groups? What is it like for you? (Prompts: What sorts of things do the participants talk about, what sort of activities do you do there?)

## Questions for focus group discussions with aged care staff

### Topic 1: Working with older survivors

What kinds of experiences have you had in caring for/working with older survivors of genocide or mass trauma? (for example: Holocaust, Cambodia, Bosnia .....

Do you think you would know if an older client was a survivor of genocide or mass trauma? How do you think you would be able to know this?

Do challenging situations sometimes arise in your work with older Cambodian people/Holocaust survivors? What kinds of situations?

What sorts of strategies/skills do you use for dealing with challenging situations?

What kinds of day-to-day situations have you found can triggered negative reactions, such as fear or anxiety, amongst your (*survivor*) clients?

Have you been in the situation of an older trauma survivor telling you about their past traumatic experiences? *Prompt:* What were the circumstances?

How did you respond to clients' disclosures about their past?

What sorts of things do you do to deal with your own emotions in these situations?

Can you tell us about the things that you have found rewarding in working with survivors?

### Topic 2. Working with survivors' families

What kinds of contact do you have with the families' of older survivors?

Do challenging situations sometimes arise in your encounters with the families of older survivors? What kinds of situations?

What sorts of strategies/skills do you use for dealing with challenging situations?

Can you tell me about the things that you have found rewarding in working with survivors' families?

What sorts of things have family members told you should be avoided when working with their parents/or family member (because of their traumatic experiences)?

### Topic 3: Attributes, knowledge, skills and training

What qualities do you think an aged care worker needs to work with Holocaust/genocide survivors?

What kinds of knowledge do you think aged care staff need for working with older survivors of genocide or mass trauma?

What kinds of skills do you think aged care staff need for working with older survivors?

Do you feel you have enough knowledge and skills for working with older survivors?

Would you know where to obtain more information about working with survivors of mass trauma and their families?

How have you learned about working with older survivors?

Have you received any formal training relating to working with older survivors and their families?

Can you tell us about that?

Was it provided by the organisation you work for now? Another organisation?

#### **Topic 4: Support**

Is there someone in your organisation that you could go to for advice about managing a challenging situation with client who is a trauma survivor?

What kind of support would you like to have from your organisation for working with older survivors?

## **In-depth interviews with services providers**

### **Topic 1. Experience of working with survivors**

Can you tell me about your experience of working with older Cambodians/Holocaust survivors?

Can you tell me about older Cambodian people's/Holocaust survivors' experiences of using aged care services?

Do challenging situations sometimes arise in your work with older Cambodian people/Holocaust survivors? What kinds of situations?

What sorts of strategies have you used for dealing with challenging situations?

What kinds of day-to-day situations have you found can triggered negative reactions, such as fear or anxiety, amongst your (*survivor*) clients?

Do the older Cambodian people/Holocaust survivors that you work with ever talk to you about their past traumatic experiences?

How do you generally try to respond to clients' disclosures about their past?

### **Topic 2. Working with survivors' families**

What kind of contact do you have with the program participants' families?

Do you ever find working with survivors' families can be challenging?

Do family members ever tell you about things that should be avoided when working with their parents/or family member (because of their traumatic experiences)? What sorts of things?

### **Topic 3. Aged care workers**

What kinds of knowledge do you think aged care staff needs for working with survivors of genocide or mass trauma?

What kinds of skills do you think aged care staff needs for working with survivors of genocide or mass trauma?

What personal qualities do you think would help an aged care worker to provide sensitive care for older genocide survivors?

## Questions about using HACC services for older Cambodians

How long have you lived in Australia? Do you have family members in Australia?

Do you live alone? If not, who do you live with?

Do family members help you with: Shopping, cooking, cleaning, personal care, transport?

Are you getting enough help from family members?

Are you (is your relative) receiving any home help from any people outside of your family?

What kind of help do you receive? How did you find out about this help?

After you found out about home help did someone come to your house to ask you questions about the sort of things you need help with?

Did that person speak your language? If no, did that person come with an interpreter?

Did that person ask you to sign some forms? Did they explain to you what the forms were about?

Have you been asked about the kind of person you want to help you? (ie. man/woman or what languages they speak). If no, would you like to have a say about who comes?

Do you have a say about when the home helper will come (what day of the week? What time of the day?) If no, would you like to have a say about when they come?

When there has been a new home helper have you been told about it before they came? Would it be better if you were told before a new person came to your house?

Have helpers ever ask you things about the past? If yes, do you mind being asked about the past?

Do you think it is important for home helpers to know something about what happened to the Cambodian people during the Pol Pot regime?

When the home helper comes to your house, does she (he) tell you what jobs they are going to do? If yes, is that important to you? If no, would it be better if they did tell you?

Do you look forward to the home helper coming to your house? If yes, why?

Thinking about the different helpers that have been sent by (*name of the agency*) to help you. Was there any helper that you particularly liked? What did you like about that helper?

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