

STEPS Together:

Conversations with people facing terminal illness

by Amanda Tay



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Abstract

Terminal illness, death and dying are universal human experiences, but discussing them can be challenging. This paper demonstrates the use of a therapeutic conversation guide, 'STEPS Together', which employs narrative practices to develop preferred identities in the face of hardships related to terminal illness. The paper also demonstrates the localisation of narrative practices so that they are culturally appropriate and resonant in Singapore.

Key words: terminal illness; death; dying; bereavement; carers; re-membering; therapeutic documents; enabling contribution; Singapore; narrative practice

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Issues in conversations with people facing terminal illness

Discomfort

People often feel uncomfortable when speaking with those facing terminal illness and death. According to Singapore Hospice Council (2021), only 20% of people feel comfortable talking with a person who is terminally ill. Lien Foundation (2014) found that for 45% of respondents, not knowing how to broach such topics was a significant barrier to death-related conversations.

Dominant discourses

Hospices are deeply situated in the medical world, so professional knowledge about how death and grief should occur, and mainstream perspectives on what is defined as problematic, are often privileged over people's lived experiences (Hedtke, 2001). People are often spoken of or defined by healthcare professionals primarily as patients with terminal illnesses, with problems to be managed. Themes such as lack of acceptance, anxiety, desire for a hastened death and collusion are almost always perceived as problematic. Referrals to psychosocial services are usually made in response to what a professional sees as being the problem. If one is not aware of these dominant discourses and practices, and their potential undesired effects, one could inadvertently overlook people's lived experiences and knowledge.

Also dominant is a focus on the needs of the person with the illness; caregivers' lived experiences are less privileged and often undervalued (Ong, 2019).

With the COVID-19 pandemic, dominant ideas about what constitutes a good death – such as passing on in the physical presence of loved ones – have not been attainable for some. However, alternative ways of defining a good death can be generated and enacted (Sanders, 2020).

Disconnection

Conversations with people with a terminal illness often miss opportunities to invite connections with significant people or figures. The lack of such invitational spaces could reflect structuralist understandings of the self as an individual (Russell & Carey, 2004). In contrast, a social constructionist perspective understands identity as a sociohistorical product that is negotiated socially (White, 2004). The structuralist perspective could overlook significant connections between a person's relationships and their social and relational identities (Russell & Carey, 2004).

People with terminal illness commonly see themselves as being 'useless' and a 'burden' to others. 'Being a burden to friends/family' is one of the top fears of Singaporeans facing death (Lien Foundation, 2014, p. 3). However, when spaces are created for people to explore their identities in historical context, and to attend to the value of contributions given and received by significant others, this can allow people to view their identities from a richer perspective that steps outside the dominant discourse of a person's value and identity being defined only by their present functionality.

The STEPS Together guide

The STEPS Together guide provides a structure to support practitioners to move beyond discomfort, and to step outside of professional or medical views of patients and problems. It invites conversations that privilege the person: their experience-near descriptions of their problems and their preferred narratives. This reflects the narrative worldview in which the person is the person and not the problem (or illness). It acknowledges significant, though often overlooked, narratives that exist outside the problem narrative (White, 2007). For people facing life-limiting conditions, maintaining a sense of identity beyond that of being a patient is crucial to their sense of dignity and resilience (Chochinov, 2012).

The STEPS Together guide applies poststructuralist sociohistorical understandings of identity, and emphasises intentional states of identity rather than internal states (Russell & Carey, 2004). 'Resilience' in this context is understood to mean richly described preferred identity conclusions and actions (White, 2004). This invites 'local and particular forms of resilience', rather than the universal ideas of resilience discussed in Western literature (Giacaman, 2014, p. 6).

Conversation prompts		Narrative maps/ practices
S	Struggles and suffering	Externalising
Т	Tracing responses	Re-authoring and unique outcomes
Ε	Enriching memories/ legacy	Absent but Implicit
Р	People on the journey	Re-membering
S	Supports needed/ steps towards contribution	Outsider witnessing, enabling contribution

Table 1. The STEPS acronym and its links to narrative practices

The STEPS Together conversation guide is suitable for use with:

- people with terminal illness, with a prognosis of less than 12 months
- · caregivers of people with terminal illness
- people referred for casework and counselling services on a nonvoluntary basis, who are usually not keen for formal/structured therapy.

Each part of the STEPS acronym can be explored:

- in a non-linear fashion
- to privilege aspects that are relevant to the person
- during short-term interventions (one to four sessions)
- to incorporate/inform casework and advanced care planning.

STEPS	Narrative therapy map	Sample questions
Struggles and suffering	Externalising	What is the pain (or other symptom) like? What has been most troubling with [experience-near description]? Why is this most troubling? How has affected your daily life (e.g. ability to do things, thinking, moods, meaning/purpose in life, activities, burden to others)? Have you encountered expectations about how you should deal with these challenges? What are some of their effects? Are they okay or not okay with you?
Tracing responses	Re-authoring, unique outcomes	I notice you took this [experience-near description] step when you experienced [experience-near description]. What was the situation as you were taking this step? What was the purpose/meaning of taking this step? What values/beliefs/sayings/life principles supported you in taking this step? Have you had other experiences of this? Have there been other situations/experiences when this step/value/saying/principle was helpful? Are there people who have observed/supported this step/value/saying/principle? How? Suppose you hold on to this value/saying/principle, would it make a difference in your next steps/situation?
Enriching memories	Absent but implicit	It's been difficult with Could this be because you've lost things (e.g. abilities/purposes/meaning/hopes) that were important to you? What are they? What was your life like before the illness? What/who has been important to you?
People on the journey	Re-membering (others' contributions to the person)	Who are the people who are important to you or have been supportive of you? How has this person contributed to you (e.g. abilities, memories, values, advice/sayings)? Why are these important? Why/how did you choose to accept this person's support/contribution?
	Re-membering (the person's contributions to others)	What might this person say about how you have contributed to their life? What does this mean to you? If this person were here or able to understand, what do you think they might say or think about the steps you are taking? What does this mean to you? What might it mean to the person?

Supports needed/ steps towards contribution	Outsider- witness responses	Were there particular parts of the sharing you identified with the most? Were there thoughts/memories that came to mind? What values/commitments might this person hold? Is there a situation in your life that contributed to why you could identify with this part of the sharing? How has this sharing made a difference to you/impacted you? What reflections have you had?
	Supports needed	What are some supports you need? What makes them important?
	Enabling contribution	I know of people facing similar challenges to you. Would it be meaningful if I could document your expertise to share with them?

Adapted for the local context from White (2007) and Freedman (2012).

Table 2. The STEPS Together conversation guide

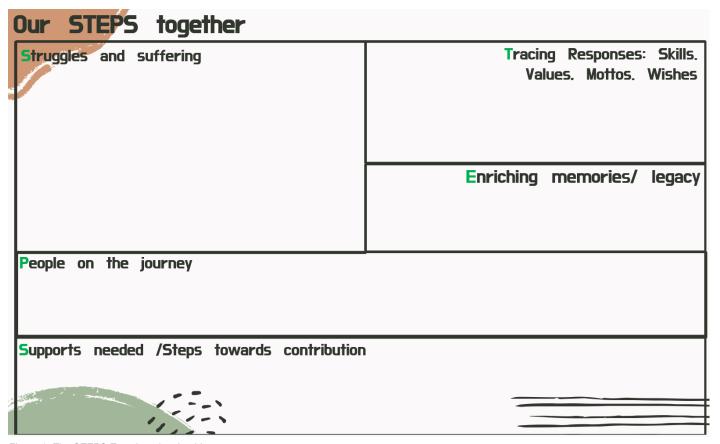


Figure 1. The STEPS Together visual guide

Key adaptations to the cultural context in Singapore

Local adaptation is crucial because ways of thinking are socially and culturally situated (Berk & Winsler, 1995). Sensitivities are required in the use of language because 'words are the world' (White, 1994, p. 30).

STEPS is an acronym to guide narrative conversations. Acronyms are familiar communication tools in Singapore.

The process of *naming* the problem has been changed to the use of experience-near descriptions. This supports naming and/or scaffolding through 'mis-naming' the issues – providing options or guessed/beginning characterisations (Hayward, 2006, p. 43). This adapted process is important because the practice of naming issues is not familiar to people in Singapore.

The term *story*, which is regularly used in narrative questions, has been changed to *experience/situation* as

Singaporeans are unfamiliar with using the term *story* to describe their particular experiences. Embedding tentative statements using experience-near language is also crucial because asking questions can be perceived to be interrogative.

Applying STEPS Together in conversation: Betty's story

The STEPS Together guide was used to structure conversations with Betty, who had terminal cancer. We first explored her *Struggles and suffering* using externalising questions, while also *Tracing responses* to these experiences using re-authoring and attending to unique outcomes. This was followed by *Enriching memories/legacy* using the absent but implicit.

Struggles and suffering

Amanda: What is the pain like?

Betty: The pain is inside and all over my body.

I have multiple tumours in my body.
I can't really talk for long. It's very painful...

What do you want to talk about?

Amanda: I heard from the nurse who referred you

that you had financial difficulties you wanted

to get help for.

Betty: Yes. I went to the agency and I got really

angry with them because they rejected my application for financial assistance. They said that [the documents/ information] didn't add up. I told them I'm dying. I'm a walking corpse. They said I shouldn't spend my savings on my son. I told them to put themselves in my shoes – if they were a parent dying. I scolded them and left.

Externalising conversations are starting points to connect with a person's experience-near descriptions of *Struggles and suffering*. People facing terminal illness are given space to describe the problem/illness and its effects on their lives. Problems are then discussed using the person's terms, rather than the language of professionals or dominant discourses (Hayward, 2013). In this way, the problem is objectified, rather than the person (White, 2007).

For Betty, externalising allowed space for experiencenear descriptions of the problem and its effects. When I asked for her description of 'the pain' rather than 'your pain', this expression was to situate her in relation to her pain. It was a starting invitation to notice aspects of her life that were not dominated by the unwanted effects of the pain.

Tracing responses

Amanda: When you scolded the staff and left,

what did that mean to you?

Betty: I am someone who is not afraid of standing

for what is right. I am an open book and

I'm not lying.

Amanda: It sounds like you are someone who will

stand up for yourself and your beliefs.

Betty: I have had this cancer since 2015 and

I've never gone for chemotherapy. I have never regretted this decision because I see some of my friends who have cancer suffering from the chemo. It's only recently that I've been in terrible pain. It's really suffering and I wouldn't wish this kind

of life on anyone.

Noticing Betty's agency in the steps she took to respond to the problem of accessing financial assistance, and asking about the purposes/values behind her actions, provided space for Betty to say more about what was important to her. This led to further descriptions of situations (like the decision to not go for chemotherapy) that were aligned to her values, leading to the development of a preferred narrative that was outside the dominant problem narrative. This preferred narrative may have gone unnoticed if the focus of the conversation were solely on the initial problem account.

Double listening allowed me to invite Betty to include unnoticed but potentially significant experiences that were out of phase with the dominant problem narrative (White, 2007). Such re-authoring conversations support people to respond to trauma and loss, including those associated with facing terminal illness. This can make a difference to how they experience the effects of the problem (Russell & Carey, 2004). People's psychological and spiritual outlook affects their experiences of life-limiting illness; their experience is not defined exclusively by the nature of the illness itself (Chochinov, 2012).

Re-authoring questions start with noticing steps the person has taken. In Singapore, people tend to describe observable actions in response to challenges. Inquiring about an experience or situation can situate these steps in the landscape of action. After such experiences or situations have been described, it often becomes easier to explore the purposes or meanings that may have supported these actions – the landscape of identity. 'Zigzagging' between the landscapes of action and identity can thicken preferred narratives (Russell & Carey, 2004, p. 27). It can also support movement along the 'hierarchy' of intentional states from the purposes that informed a particular action to the commitments people stand for in life more broadly (Russell & Carey, 2004). The more clearly someone can articulate what they stand for, the more likely it is that they will be able to determine additional steps they can take in life (Russell & Carey, 2004).

Re-authoring conversations can be useful with people who may not be comfortable sharing their *Struggles and sufferings*, including those who have been labelled as having 'difficulty coming to terms with illness'. *Tracing responses* can support the person in facing *Struggles and sufferings*.

Enriching memories

Amanda: It sounds like this recent period has been

really tough for you with the constant pain. Does it mean that you had a different life

in the past?

Betty: I ran a very successful social escort

business, and I was very rich ... There is so much to share that I could write a book

about it!

Amanda: Actually, if you would be keen, we could

explore writing about your life together.

Betty: Yes, that is my wish. I want to write a

book about my life as I believe it will

impact others.

When Betty shared her value of 'not wishing this kind of life on anyone', I was curious about what was absent but implicit in this statement, and about the life she had previously. It turned out that she had a life she valued and gained lessons from, and that she would find it meaningful to share this as part of her legacy.

Inquiries about the absent but implicit are helpful in *Enriching memories/legacy*. The absent but implicit can be explored when people are depressed or distressed, especially as they undergo loss. These inquiries can provide opportunities to reconnect with valued and meaningful aspects of life, and to open possibilities

including legacy work. Legacy work can also be crucial to support the bereaved: maintaining connections with the deceased can be significant in responding to death-related losses (Moxley-Haegert, 2015).

Double-storied conversations contributed to Betty gaining increased clarity about her values, and this provided orientation for her next steps: she would write a short book about her life on her terms. Myerhoff (1982, p. 232) described how it was significant for people to 'exercise power over their images, in their own eyes and ... in the eyes of whoever may be observing them'. Having such personal power might bring one to a 'greater fullness of being' (1982, p. 232).

Betty's renewed agency contrasted with her position at the beginning of our conversations, when she described herself as a 'walking corpse', in 'terrible pain', and as not knowing if she had any goals or wishes.

Betty was supported to complete the short book, and this honoured her principles of living, which challenged conformity and normality, but stood for certain values (see Denborough, 2014). When I explored the meaning of writing and publishing the book, Betty shared that it was a way of taking a stand as a woman. It was a way to value herself, and an act of resisting shame.

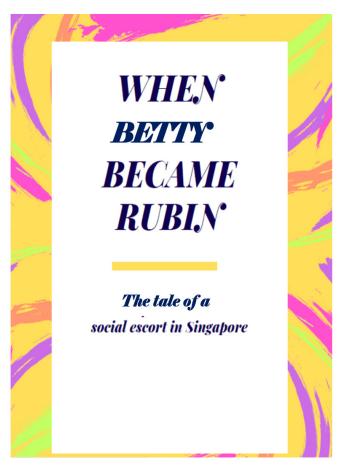


Figure 2. The front cover of Betty's book

People on the journey and steps towards contribution

Myerhoff proposed using existing community rituals to support people to make contributions to others and experience rich acknowledgment (Myerhoff, 1982, as cited in Denborough, 2008, pp. 59-60). A book review process and book signing ceremony were used as community rituals for Betty. As Betty shared the final draft of her book with others, I partnered with her to gather significant people (her son, best friend and former staff) to respond to the book. Their responses bore witness to the impact she had on them, and their words were published as testimonials in the book. Subsequently, a ceremony for signing and distributing the printed book took place on Betty's birthday in the presence of her son and best friend who spoke about their experiences with Betty and what they had learnt from her.

Sharing the book with her son enhanced their connection and enabled further contributions to one another. Betty said:

I was surprised when my son spoke to me. I asked him, 'Son, did you read the book? Did you get upset about anything?'

He said, 'No, everything is raw, Mum. Can I give you a hug? I'm proud of you as a mother. You've always been my strength. I see you as a strong woman.'

After the book ceremony, Betty's son became more involved in caring for her and took significant steps to support her care at home that was within his capacity.

Applying STEPS Together to practices of connecting and collectivising: Ella's story

Preferred identities can be supported and thickened by connecting people with significant People on the journey through re-membering conversations, and through Steps towards contribution drawing on outsider witnesses and enabling contribution. This is consonant with a poststructuralist worldview that sees identity as storied and relational (Freedman, 2014). People can reconstruct their lives in preferred ways within relationships (Freedman & Combs, 1996).

Ella was referred in relation to caregiving challenges. She had brought her mother out of a nursing home

to live with her in her final months because this was what her mother would have wanted. Medically, her mother was classified as having no mental capacity. Our conversations incorporated aspects of STEPS Together, beginning with Struggles and suffering, and emphasising People on the journey.

Struggles and suffering

Amanda: How have you been?

Ella: It's been like a rollercoaster. My mother has been rejecting medication, losing weight,

not being able to sleep at night.

Amanda: What has been most troubling for you while

caring for your mum?

Ella: I am afraid to hear from the doctor that

> Mum is really dying. I'm not sure if I'm prepared. I'm sad that when I contact my siblings about Mum, they sometimes don't respond. I am the only one who

cares for her.

Amanda: What would it mean for you to have your

siblings' support?

Ella: I would feel stronger and more confident.

At least I would have someone to talk to.

People on the journey

Are your immediate family members Amanda:

supportive of you caring for your mum?

Ella: My husband and children are supportive of

my efforts to care for my mother.

How have your husband and children been Amanda:

supportive of you?

Ella: My husband and children do not expect

> too much attention from me because I am caring for mother [shares other examples

of support].

I'm wondering, as your children observe Amanda:

you caring for your mum, what do you think

they would say or think about it?

Ella: My children would say that they want to be

like me and care for others.

This conversation was taken up at a later date.

Amanda: It sounds like your husband and children

have been very supportive of you caring for your mum, even though your siblings haven't been as supportive as you would

have hoped.

Ella: Yes. They are supportive of me. My

husband told me to not hold on so much to the feeding and sleeping times, so now I don't stress over these as much. When she is not hungry, there's no need to

force her.

Amanda: Are there any sayings that you and your

family hold on to that help you with caring

for your mum?

Ella: We have a saying: 'we know that she is

going away, but we don't act like she's going'. We stopped thinking about how many more months she has. 'If there's still a day, there's still time to be happy.' I am learning to let go when I see her suffering.

Amanda: Why is 'letting go' important to you?

Ella: I want to be happy and at peace. When

I'm more at peace, I'm more energetic and

confident in caring for my mother. I'm not as depressed and tired as

I was before.

Amanda: How do you think your mum might feel

or think if she knew that this

was happening?

Ella: When I am more at peace, my mum smiles

and will blink her eyes. I feel that she can understand that she is not a burden to me. She can still lift her head for me to kiss her

forehead.

These conversations elevated the memberships of Ella's husband and children in her club of life, and explored ways they contributed to Ella and Ella's contributions to them. The later conversation elicited further of ways that Ella's husband and children had contributed to her in terms of sayings and ways they helped her to be more at peace – and how in turn, her being 'at peace' contributed to her mother's smile and not feeling like a burden.

Re-membering questions invite the presence of *People* on the journey. Identifying mutual contributions is particularly supportive for people who feel isolated.

Inquiries about *People on the journey* offer possibilities for connecting with historical, nonverbal or hypothetical contributions from people who may no longer have mental or physical capacity to contribute or who are no longer alive. Re-membering can be used to privilege the preferences of people who do not have the capacity to participate in planning discussions about their care (L. Pederson, personal communication, September 17, 2021).

Ella reported that these conversations had led her to taking active steps to get support from significant people in her life.

Amanda: How do you feel about our conversations so

far?

Ella: It's very good. The first time I was really

depressed. I had decided not to talk to anyone because I felt embarrassed. I didn't even talk to my husband. After our initial conversation, I started to talk

to my husband.

Amanda: What enabled you to take the step of talking

to your husband?

Ella: I need someone close to me. He is my

husband. It is very important to let go and talk to the right person. Talking to you and talking to my husband made

me feel better.

Ella went from feeling 'depressed' and 'alone' in her *Struggles and suffering*, to being someone 'at peace', 'more confident' and with people she could confide in. This is what she had hoped for. In turn, Ella's mother gained greater social support from Ella. Such social dignity is important for people with a life-limiting illness (Chochinov, 2012).

Outsider witnessing and Steps towards contribution

Given the sense of isolation that Ella initially expressed, I shared with her a collective document I had co-authored with people facing terminal cancer. In the document, Wong stated:

I try to make my wife understand that I still love her and will not abandon her. Without fail, every day after work, I massage her legs and move her limbs to help her exercise. I massage her face. Massaging her is also a chance for me to get some exercise. I stay with her and talk to her and hug her. Ella was invited to provide an outsider-witness response to the collective document. Ella's responses were shared with Wong, and Wong's responses to Ella's responses were later shared with Ella.

Ella's response to Wong's testimony

- Expression what Ella identified with:
 'Expressing love and care in practical ways.'
- Personal resonance: 'Wong's words, "I still love her and will not abandon her", are what I feel.
 I don't want my mum to feel that she's a burden.
 I want her to know that I do this because she loved me, so now I want to show that I love her.'
- Transport: 'Before reading this, I would usually go into the room and say, "Ma". But after reading Wong's testimony, I really hug her. I kiss her and say, "I love you". She gives a response that she knows I want to hug her. At the end of the day, she knows that I love her.'

Wong's response to Ella's response

- Expression: 'It should be two-way. This is a time when you have a chance to return love to your mother, to thank her.'
- Personal resonance: 'When I visit my mum,
 I give her a hug and she's very happy. She
 cannot talk much. I'm also doing this with my
 mother, not just for my wife.'
- Transport: 'I feel happy that I'm doing the right thing. Tell Ella that if she has anything to share with me, I would like to hear it. I want to keep on learning.'

Through this collectivisation of experience, caregiving became more meaningful for Ella, and a sense of solidarity was generated. Ella said:

When I looked through the collective document, I cried because this is what I go through. I learnt that I am not alone and that I'm doing the right thing. It took me three days to read the collective document. My life journey is good because I chose to be caregiver to my mother. I feel that I'm not a useless person.

Through the facilitated retellings and the personal resonance of their actions and values, both Ella and Wong gained a sense of solidarity and acknowledgment of their preferred identity claims as caregivers committed to *learning* to love and care for their loved ones in practical and tangible ways. These preferred identities continued to be sustained even with subsequent increases in caregiving challenges.

Research suggests that insight into personal values can enhance caregivers' meaning-focused responses beyond external factors (Tan-Ho, et al., 2020).

Enabling people to contribute to one another positions them as authors of knowledge about their lives (Caputo, 1993, as cited in Epston, 2011, xxix). It has the therapeutic benefit of making their expertise more visible to themselves and others, and strengthening initiatives that make further action possible (Denborough et al., 2006). Creating contexts for people with similar difficulties to make contributions to each other shows that sometimes 'the solution is not only personal' (Denborough, 2008, p. 192). This is a move away from seeing people as being in need of help that can only be offered by professional services (Denborough, 2008). Such exchanges can be facilitated through outsider witnessing structures (Denborough et al., 2006). These decentre the therapist and privilege the macro-world of life over the micro-world of therapy (White, 2011). The use of archives of client 'wisdoms' (Epston, 2001, as cited in Denborough, 2012, p.47), such as the therapeutic documents shared with Ella and Wong, also highlights the effectiveness of solution knowledges from beyond the therapy room.

Applying STEPS Together to discuss bereavement: Tham's story

The STEPS Together guide can be used as a framework for conversations about bereavement (see Dulwich Centre, 2008; Fareez, 2015 to incorporate relevant aspects of bereavement inquiries within the STEPS Together framework).

The STEPS Together guide was used to facilitate a double-storied account of Mdm Tham's bereavement experiences – understanding her *Struggles and suffering* while *Tracing responses*. Connections with *People on the journey* were facilitated by inviting the deceased and other significant people into the conversation. Someone's personhood is not erased by death and can live on in the lives of those significant to them (Epston & White, 1992). The dominant discourse of grieving involves saying good-bye. However, 'saying hullo again' can be significant when struggling with grief (White, 1998). The following is an excerpt of our conversation.

Struggles and suffering

Tham: He passed on too quickly. I am very sad. It's hard to let go, but when I saw him

suffering, I assured him that it was okay to go because I didn't want him to suffer.

Amanda: It sounds like it's been hard that this

happened so quickly, especially since

he has been your life partner.

Tham: He has been a big part of my life. I am

really heartbroken that he is no longer around. Sometimes I feel overwhelmed,

and I think about it a lot.

Amanda: What has it been like since his passing,

since he has been such a big part of

your life?

Tham: I have had to be more independent.

I used to depend on him for things like getting around Singapore via public transport. He was very concerned about

how I was going to cope.

Tracing responses

Amanda: It sounds like you've learnt how to get

around using public transport. How did you

manage to learn this?

Tham: I have the skill of asking people for help,

and of learning new ways of coping. In the past, I didn't know how to take the bus,

but I learnt.

Amanda: Why is it important to learn new ways

to cope?

Tham: I learnt how to take care of myself because

I do not want my husband to be worried about me, and I want him to be at peace in

the afterlife.

A double-storied therapeutic letter documenting our conversation was sent to Mdm Tham.

Dear Mdm Tham.

You shared that you felt your husband passed away too quickly. You used to be very dependent on him ... Your husband has been a big part of your life and you're heartbroken to lose him. Before he passed on, he was worried about you and your son. You are also worried about how you would continue to live life. But you have your own knowledges and ways of coping.

You are capable at work and your boss appreciates your abilities.

You have friends who ask you out to meet them. You have an ability to get along well with people and the skills to build good relationships. You learnt these from [history of this skill].

You have the ability to learn. You didn't know how to take the bus, but you learnt how.

You have learnt how to take care of yourself. You don't want your husband to worry about you; you want him to be at peace in the afterlife. Even though it was hard to let go, you comforted him so he would not worry and could leave peacefully.

When you miss your husband, you look at his photos and talk to his ashes.

At times you feel you're thinking too much, but you have learnt that you will slowly adjust to this.

Tham read the letter several times, and said, 'this is me'. The letter brought much comfort to her in her struggles as it helped her remember who she is. Hence, Tham was confident that she no longer required therapeutic sessions. The self-sustaining effect of this letter is in line with a report that therapeutic letters could account for 52.8 % of positive outcomes of therapy (Nylund & Thomas, 1994, p. 4).

The conversations in this paper are steps in my journey of learning how narrative practices can be adapted to enhance people's preferred narratives and privilege their collective resilience in facing hardships. Practitioners can adapt this guide to their own contexts.

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