



PRINCIPLE ONE

Good supports provide me with real choice and create a sense of control

“Caring is overwhelming - my ability to think and plan is diminished. I am in survival mode and reactive. Let me talk and show me the different paths I can take.” CARER

Consider the following when seeking to support older people, their carers and families

| | |
|--------------------------------|---|
| It is important that... | There is support where I can get information and make informed choices. I want to be considered as a decision maker in this process. |
| I need you to... | Listen to me so that you can understand what I am going through. Guide and reassure me through my journey and acknowledge my experience. |
| Make me feel... | That I am valuable, being heard, not alone and that I will be OK through your support |
| Please understand... | I am suffering whilst managing yet can't always see the way ahead. Although I may seem to be coping on the outside on the inside it is a different story. |

PRINCIPLE TWO

Good supports respond holistically in relation to myself and those around me

“At times I feel completely out of the circle - it’s an overwhelming responsibility. I’ve withdrawn myself from friends and I choose who I see with my situation. I need care too but nobody cares for me.” CARER

Consider the following when seeking to support older people, their carers and families

| | |
|--------------------------------|---|
| It is important that... | You recognise me as part of the solution and understand my stress and anxiety. Having support and someone to talk to in times of need helps me to cope. |
| I need you to... | Make time to listen, be open to what I share and encourage me. Respect me as a carer and guide me towards supports that provide for what I need. |
| Make me feel... | That caring has value and I am not a problem to be solved. I need to be around people who know what I am going through and see me as a person in my own right. |
| Please understand... | I am not always at my best because I am stressed and time poor yet need connection with others to feel less alone. This is my life, I don't have another and it can feel like there is no escape. My needs have been coming last. |



PRINCIPLE THREE

Good supports enable me to identify
needs and make choices aligned to
values and preferences

*“As a carer I get excluded from
communication sometimes and told
‘You are not the client’. But I’m the one
doing it 24/7. I need to be included in
communication to do my work.” CARER*

Consider the following when seeking to support older people, their carers and families

| | |
|--------------------------------|--|
| It is important that... | I have a trusted service or health professional that guides me towards what is available. Support me to think clearly about future options and how to build supports. |
| I need you to... | Consult with me and make choices clearer to me by sharing information. Show me empathy and allow me to arrive at decisions without feeling rushed. |
| Make me feel... | That I am important and am being heard. That I can make good choices and it is OK should these change at anytime. |
| Please understand... | Advice is not about control and that what I am doing is the best I can. What is obvious to you is not always clear to me. Work with me as I am scared and feel out of control. |



PRINCIPLE FOUR

Good supports combine formal and informal resources

“When you’re a carer, your networks become fellow carers - no explanation, no validation needed. How else do you know what you are going to need to know?” CARER

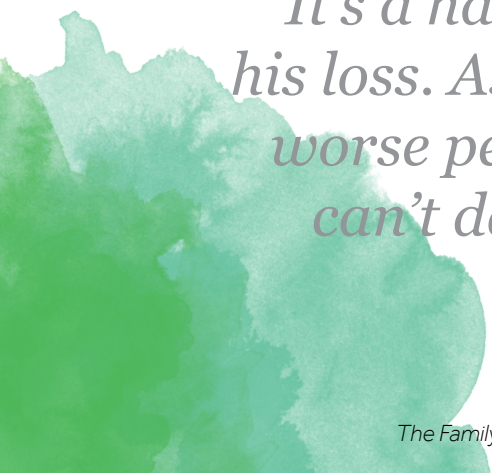
Consider the following when seeking to support older people, their carers and families

| | |
|--------------------------------|--|
| It is important that... | The support I receive is from competent, culturally aware and skilled individuals. I want it to be seamless and accessed easily without fighting for it. |
| I need you to... | Tell me clearly what you can offer and help me to be aware of limitations. Be transparent and guide me towards making choices for what I need. |
| Make me feel... | I am noticed, understood, supported and emotionally nourished. Help me find time for myself and build my confidence. |
| Please understand... | I need linked supports where I can be involved. |



PRINCIPLE FIVE

Good supports recognise and respond to multiple layers of complex grief and loss



“It’s a half life like I am already grieving his loss. As my husband’s condition has got worse people have dropped away - they can’t deal with how he is now.” CARER

Consider the following when seeking to support older people, their carers and families

It is important that... People recognise the hole in my life when no longer caring and that grief is a constant process. Where do I go next as I have lost close connections over time?

I need you to... Be aware that the process is different for everyone so address my needs at the time and include what I will need going forward.

Make me feel... That I don't have to be strong all the time. That I can cope and that I am supported to find my way in looking after myself.

Please understand... That I am fearful of what the future holds.



PRINCIPLE SIX

Good supports enable smooth transitions across services and systems

“There is a lifetime of services and we have to anticipate beyond immediate needs. As a carer I’m playing the long game all the time.” CARER

Consider the following when seeking to support older people, their carers and families

It is important that... Services talk to each other while including me in accessing the right support. I need the system to be user friendly as I am already struggling.

I need you to... Understand where I am currently with supports as this helps us both to navigate from a problem to a solution.

Make me feel... You value my time, my efforts and my experience. Treat me with empathy and sensitivity.

Please understand... Checking information with me helps with decision making and provides transparency which is so important.