



Person-Centred Emergency Preparedness (PCEP)

A Process Tool and Framework for Enabling Disaster Preparedness with People with Chronic Health Conditions and Disability

USER GUIDE

PREPARE NSW (2017 – 2018): CO-DESIGNING RESOURCES FOR COMMUNITY HEALTH AND DISABILITY SUPPORT PROVIDERS ON PERSON-CENTRED EMERGENCY PREPAREDNESS.

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Further Information: <http://sydney.edu.au/health-sciences/cdrp/projects/PREPARE-NSW.shtml>



Image: Woman on verandah overlooking rural scene

“ **Hum, that’s what they’re always telling us on the wireless isn’t it? Have a plan! You’ve got to have a plan. Well, I’m afraid I haven’t got a plan.**

Yes, well I have often wondered, uh, uh, uh, what I would do? And you see, we’re up high here, and there are steps at the front, and at the back door. There were four steps up, and my son made a ramp. So, I can go out the back way. But if the fire was racing up from the back I’d be, um, a bit scared to go out the back way. And I can’t go out the front way.

No one else tells you. Your children don’t, or my children don’t talk to me about, crises, or preparation, or anything like that. And, and not many, not many friends would talk about it. They would think it was a bit personal, and, and you’ve got so many other things to talk about. ”

Marj

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Disasters triggered by natural hazards are unpredictable. When disasters and other emergencies do happen, being prepared can reduce the loss of life, property and possessions (NSW SES, 2015). Being prepared helps people to respond better and recover faster. We all need to be ready and know what to do. People with disability and chronic health conditions may need additional support, resources, or advocacy to enable their preparedness and increase their resilience in the face of disasters and other emergencies.

Person-Centred Emergency Preparedness (PCEP): A Process Tool and Framework

People with chronic health conditions and disability need to consider how they will manage their functional capabilities and support needs during an emergency (Gershon et al., 2013; Goodhue et al., 2016; Kailes & Enders, 2007; McClure et al., 2011; Rooney & White, 2007).

The PCEP tool is designed for use by community health and disability providers to enable emergency preparedness in others. The PCEP can be used to facilitate meaningful conversations with clients in the community that raise awareness about emergency preparedness to:

- improve emergency preparedness for people with chronic health conditions and disability
- reduce negative consequences of disaster triggered by natural hazard emergencies, and
- improve recovery following a natural hazard event.

A series of three videos provide illustration of PCEP in action. They accompany this user guide.

Functional Capabilities and Support Needs in Emergency Situations



A client and community health care provider demonstrate PCEP. They engage together in the process to identify Marj's functional capabilities and support needs, first in everyday life, then in the context of a natural hazard emergency.

Emergency Preparedness is a Process



A client demonstrates PCEP as an emergency planning process. John shares specific worries he has in three functional areas: management of health, assistive technology, and living situation. He shares the preparedness actions he has taken and his current stage of self-advocacy as he furthers his preparedness plans in collaboration with his disability support provider.

Key Features of Person-Centred Emergency Preparedness



Project Leader, Dr Michelle Villeneuve explains the key features of the PCEP process tool and framework and shares what we learned from field testing this tool together with service providers and their clients.

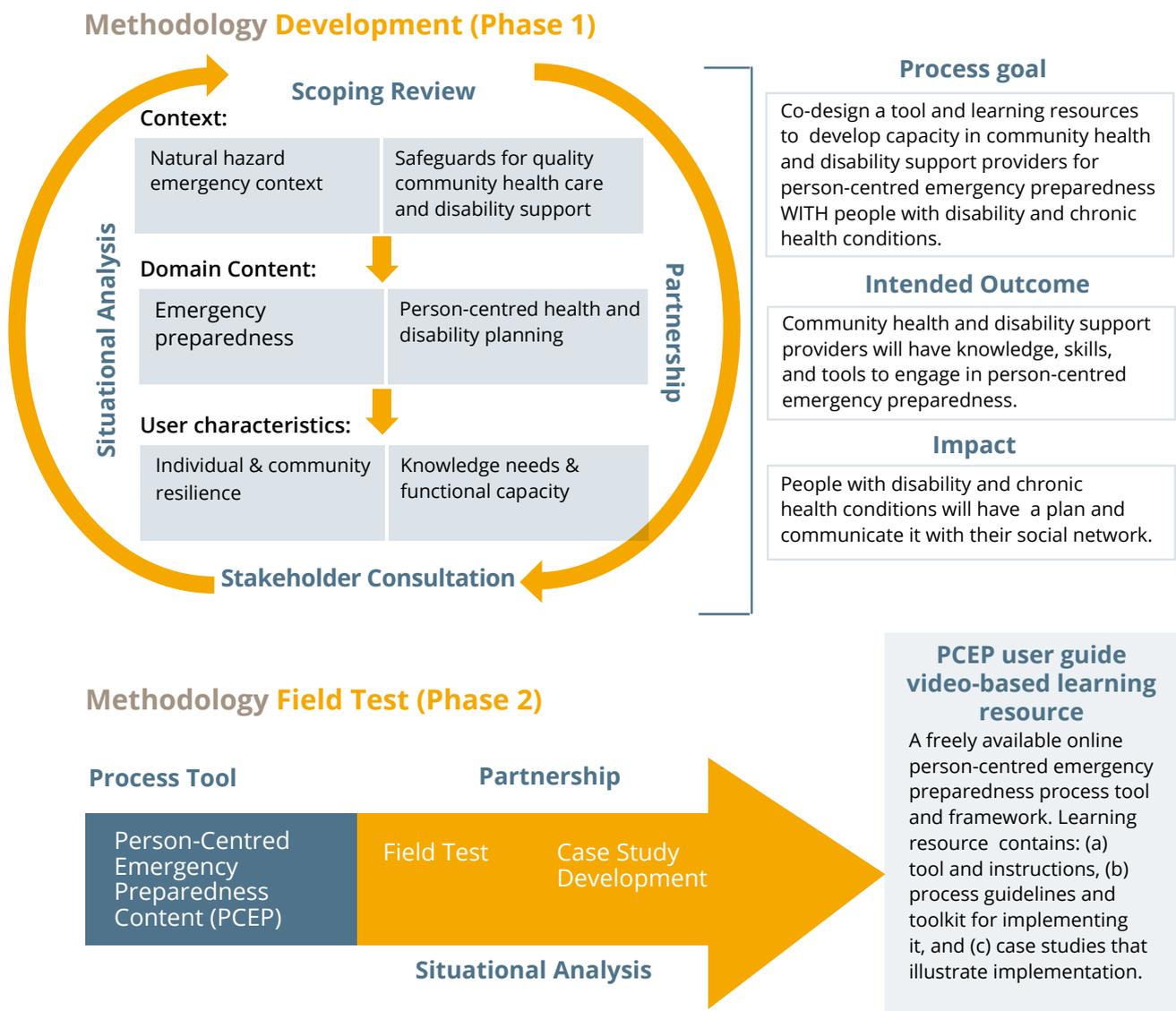
These videos can be accessed at: <http://sydney.edu.au/health-sciences/cdrp/projects/PREPARE-NSW.shtml> and <http://collaborating4inclusion.org/prepare-nsw/>. They are also available on Vimeo and YouTube.

Development of the PCEP Process Tool and Framework

The Person-Centred Emergency Preparedness (PCEP) process tool and framework was developed through a co-design process involving 115 participants including stakeholders from the disability, health, and emergency management sectors in NSW, Australia. It was field tested with people with chronic health conditions and disability and their community-based service providers.

This project focused on the: (a) technical capacity of providers to enable person-centred emergency preparedness, and (b) functional capacity of health and disability organisations to embed the PCEP into organisational practices.

The following figure provides an overview of the co-design methodology which integrated knowledge creation with knowledge application (Graham et al., 2006) to ease uptake of the PCEP into practice.



Acknowledgements

Community Partners

Frontline staff and managers offered their time and expertise on testing and refining the PCEP. Special acknowledgment is paid to the following people and organisations who supported and enabled participation of their staff and clients in our field test of the PCEP in the Mid North Coast Region of NSW.

They include:

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Deb Fox – May Home Nursing/Care Service Manager

Rhonda Guest – Regional Coordinator, Risk Reduction/Healthcare/Mayo Private Hospital, Forster Private Hospital and Mayo Home Nursing

Healthcare/Mayo Private Hospital and Mayo Home Nursing

Jonathan Holt – Acting General Manager/ Community and Aged Care Services, Greater Newcastle Sector, Hunter New England Health

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We want to thank all of those people who contributed to our video-based learning resources and user guide. Their experiences of engaging in person-centred emergency preparedness made this learning resource possible.

Advisory Committee

The project advisory committee included representatives from the following agencies who provided advice from a national, state and local perspective. These contributions informed and guided the co-design process.

NSW Office of Emergency Management,
Department of Justice

Australian Red Cross

Deaf Society of NSW

Department of Social Services (Australian Government)

Fire and Rescue NSW

Local Government NSW

Ministry of Health (NSW Health)

National Disability Insurance Agency

National Disability Services

NSW Health Emergency Management Unit,
Office of the State Health Services

NSW Council for Intellectual Disability

NSW Family and Community Services

NSW Office of Environment and Heritage

NSW Rural Fire Service

NSW State Emergency Service

People with Disability Australia

Physical Disability Council of NSW

Victorian Council of Social Service

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DISCLAIMER: THE VIEWS EXPRESSED HEREIN DO NOT NECESSARILY REFLECT THE VIEWS OF THE NSW GOVERNMENT, UNLESS THE VIEWS EXPRESSED IN THE PROJECT MATERIALS HAVE BEEN PUBLICLY SUPPORTED BY THE GOVERNMENT OR GOVERNMENT AGENCY.

Pseudonyms have been used throughout this user guide to protect anonymity of participants.

PCEP: Principles & Actions

Emergency Preparedness

- The steps you take to make sure you are safe before, during and after a natural disaster or other emergency.
- Requires that you have the capability to plan and act together with your support network to protect against, quickly respond to, and recovery from emergencies.
- Must take into consideration how you will manage during loss of essential services (e.g., utilities, transportation, food supply) and supports (e.g., community-based disability support services, home nursing, personal care) that you rely on every day.

The 5 emergency preparedness steps that people can take are: (NSW SES, 2015)

1. Know your local hazard risk
2. Make a plan now for what you will do in an emergency situation
3. Get your Home ready
4. Be aware
5. Look out for each other

Disability Inclusive Disaster Risk Reduction (DIDRR)

DIDRR is about ensuring that people with disabilities have the same opportunity to access emergency preparedness information, to participate in emergency preparedness programs in their community, and to be included as a valuable stakeholder in all phases (preparedness, response, and recovery) of local community disaster risk reduction.

More information is available at:

DIDRR Guidelines: https://sydney.edu.au/health-sciences/cdrp/projects/Emergency%20Preparedness_brochure_August2017_WEB_ACCESS.pdf

DIDRR Video: <https://www.youtube.com/watch?v=qCWUEiAVii8>



Image: Health care provider and client discuss emergency preparedness during home visit

The Capability Approach

(Nussbaum, 2011)

- Focuses on how structural factors, the environment, and personal characteristics interact to determine a person's opportunity to make valued choices.
- Allows for strengths-based thinking about opportunities and choices that people have in an emergency situation and the factors that enable or limit those choices.

Action

Service providers can

- Facilitate client-led discussions about functional capabilities and support needs using the PCEP framework.
- Advocate for access to resources that increase resilience by expanding the opportunities and choices that individuals can make before, during, and after an emergency situation.

Person-Centredness in Emergency Preparedness

- Refers to a way of interacting with people in a manner that meets their needs, gives them choice and control, and engages them so that they have ownership over decisions and actions.
- Person-centredness is important for ensuring meaningful inclusion in emergency preparedness.

Action

Service providers can

- Facilitate and guide by encouraging clients to talk about their valued choices (e.g., what is important to them, how they spend their time, where they go, what they do and who they do it with).
- Prompt discussion through reflective, open-ended questions (e.g., Can you tell me more about that?; What do you enjoy most about that?; What challenges have you experienced?)

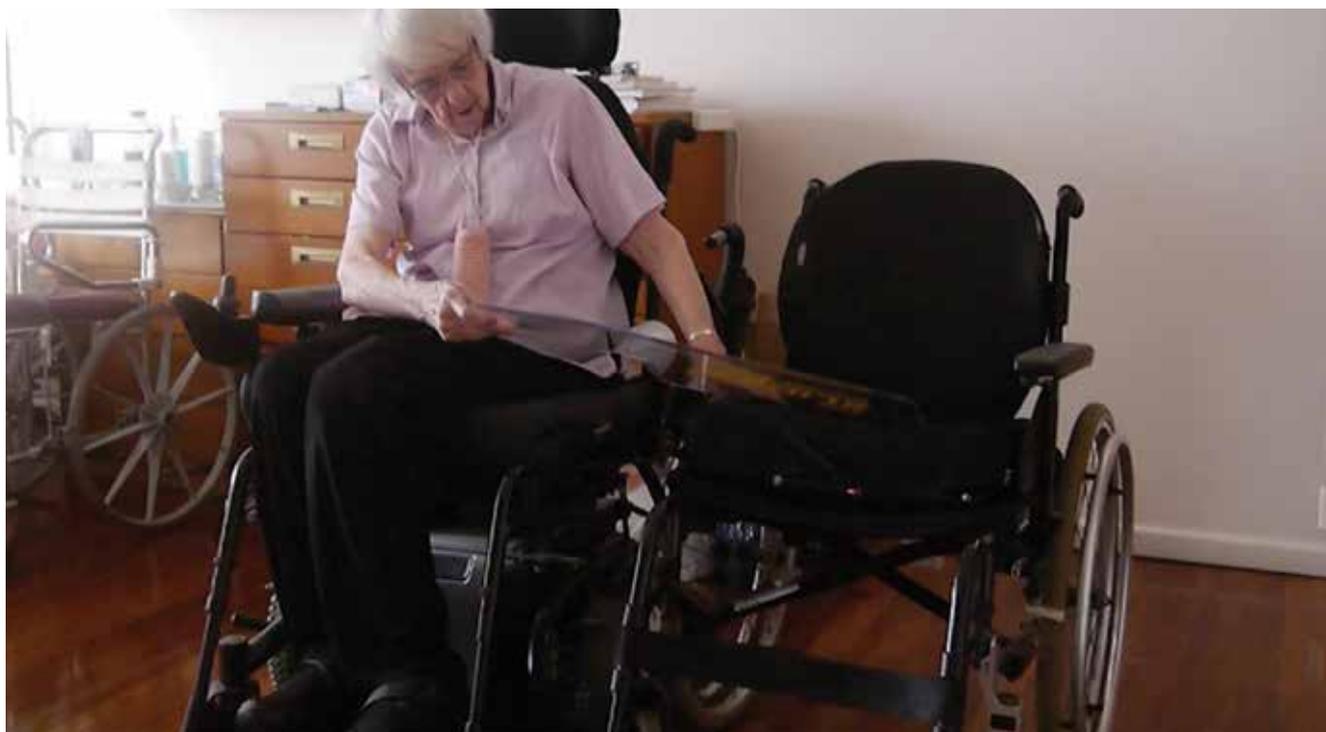


Image: Woman demonstrates independent transfer from power to manual wheelchair

The Transtheoretical (Stages of Change) Model

(Prochaska, DiClemente, & Norcross, 1992)

- People change their behaviour through stages of action. Preparedness is a process by which people take actions incrementally.
- Emergency preparedness conversations will be different for people in different stages of change. For example, action-oriented information sharing about emergency preparedness may be quite effective with individuals who are in the preparation or action stages but may be ineffective for those in the precontemplation or contemplation stages. These individuals may not yet be aware of the need to be prepared.

Action

Service providers can

- Reflect on their own stage of preparedness, as a fundamental prerequisite to enabling emergency preparedness in others.
- Use the reflective questions in the PCEP framework to enable conversations between providers and their clients.



Image: Disability support providers and emergency managers share information about local emergency preparedness and community-based supports and services.

Key point: It is important to remember that problem-solving for a person can undermine agency. Instead of directing the conversation, think of yourself as a facilitator; working with the person and supporting them, where necessary, using prompts and reflective questions, or providing information that the person may not know, rather than doing the thinking for them.

Using the PCEP tool

The Tool is made up of four stages to facilitate emergency preparedness for people with chronic health conditions and disability:

1. **Ask reflective questions to determine individual level of emergency preparedness**
2. **Engage in interactive discussion about functional capabilities and support needs in everyday life**
3. **(Re)Consider functional capabilities and support needs in the event of a home fire or natural hazard emergency**
4. **Communicate the plan**

Community health and disability support providers are in an optimal position to facilitate person-centred emergency preparedness (PCEP) with their clients because they have:

- in-depth knowledge of the individual clients they serve, their functional capabilities and support needs, their family and community context
- pre-existing relationships with clients and their family/social networks
- regular, routine interactions
- local area knowledge of the community

To contribute effectively to PCEP providers need:

- knowledge about natural hazard risks
- emergency preparedness strategies, and
- the resources and tools to enable emergency preparedness in others



Image: Health care provider and clients discuss making a plan and getting an evacuation kit ready.

Key point: There are no right or wrong answers to this process. Use what you know about the client and his or her context. This brainstorming should take place over time during your everyday client interactions.

1. Ask reflective questions to determine individual level of emergency preparedness

Stages of Preparedness

Stage	Description	Probing Questions
Precontemplation	Individuals have no intention to change behaviour in the near future; they may not be aware that change is needed	Have you thought about planning for emergencies at all? Have you experienced a natural hazard emergency?
Contemplation	Individuals are aware that a problem exists and are seriously thinking about overcoming it, but they have not yet made a commitment to take action	Have you tried to learn or find more information about how to prepare for emergencies?
Preparation	Individuals intend to take action and have started to make some changes.	Do you have an emergency kit? Have you gathered supplies or considered evacuation routes in an emergency situation?
Action	Individuals modify their behaviour or environment to overcome problems and reach certain goals	Have you taken action to make a plan for yourself, family, or household?
Maintenance	Individuals maintain behaviour changes for at least six months or more.	Have you updated your emergency plans, discussed your plan with others, or restocked your supplies for emergencies in the past 3-6 months?

(Adapted from Paek et al., 2010)

Key point: Think about your own level of preparedness and the client's stage as a starting point for a discussion.

My level of preparedness is:



Examples of Service Provider Stage of Preparedness

Community-based care providers may be at very different stages of preparedness. Consider the following examples:

Janice

When talking about emergency preparedness with some of the care coordinators at her work, Janice realised that if a person chose to stay when there was a bushfire warning to evacuate, they would be choosing to defend their home. Janice said, *"I've buried my head in the sand for twenty years. I've only, just this year, got my evacuation documents and plan together. This is the first time in 20 years since moving to Australia."*

Personal preparedness:

Janice is in the **preparation stage**, having started the process of gathering important documents and initiating a plan for her family and household. However, she continues to contemplate more complex scenarios and what this would mean for her own preparedness and that of the clients she serves.

Darlene

Darlene moved to the mid-north coast from Sydney five years ago. Since that time, she has experienced two natural hazard events: a bushfire that blocked the highway so that she couldn't get home from work until after 9.30 at night and a flood while on holidays where she and her family had to shelter-in-place at their campsite for an extra few days. Darlene's experiences were instrumental in her desire to bring emergency preparedness programs into her work and she is an advocate of preparedness for clients at the home health service she manages.

Personal preparedness:

Darlene is well aware of the local risk, and disruptions that can be caused by natural

hazard events. Not only does she have a communication plan for connecting with her family in the event of an emergency, she is taking actions on behalf of her clients to formalise emergency preparedness in the home health care service. Darlene is at the **action and maintenance stages** of preparedness.

Carolyn

Carolyn has lived in Regional NSW all her life. Admittedly, she hadn't thought about planning until a bushfire threatened the home of a family that her disability organisation supports. This made Carolyn reflect, not only on the preparedness of the family, but realised she did not have a plan for her own household.

Since then, Carolyn has had conversations with her adult son (who has functional support needs in the areas of mobility, personal support, and independent living) about emergency preparedness and has made plans for where they would go if they needed to evacuate. Carolyn now has an emergency kit in the boot of her car. Carolyn recently reflected that this planning was done over a year ago, and now she needs to review her plan

Personal preparedness:

Carolyn has actively initiated conversations with family members about their preparedness plan, and also taken action to create an emergency kit, and so is at the **action stage**. Because she has not yet reviewed her plan she is not at the maintenance stage.

Examples of Client Stage of Preparedness

Jason

Since having the opportunity to talk to his Care Coordinator about his preparedness, Jason has taken a number of actions to become prepared. He has discussed his medications with his family physician who helped him to create an online My Health Record. Jason can use My Health Record to access prescriptions if he is unable to get to his Doctor or local Chemist. Jason also knows that power outages will impact his capacity to charge the battery on his motorised wheelchair or adjust positions of his electric bed. Jason is planning to get a generator and is currently advocating for funding, with support from his disability provider. Jason knows how to use generators and how to direct its operation (including storing petrol, etc.). His planning includes consideration of his mother who has a chronic health condition and who is his primary support.

Personal preparedness:

Jason is at the **action and maintenance stages** as he has taken action for his preparedness and has been actively advocating for a generator.

Margaret

Margaret regularly hears on the radio about the importance of having a plan, but admits that she currently does not have one, although she knows she needs one.

Personal preparedness:

Margaret is at the **contemplation stage** as she has thought about the importance of a plan but, as yet, has not taken any preparatory actions.

Gillian

A few years ago, Gillian became isolated at home due to flooding. Support staff needed to be air lifted into her home to provide her needed daily care and support for three days - until the flood waters subsided. This experience caught Gillian's family off guard. Since then, Gillian's family have purchased a wheelchair-accessible vehicle so that they can evacuate early when necessary. Her family have also purchased a generator so that they can run the house water pump and sustain use of Gillian's electric bed.

Personal preparedness:

Prior to their experience with the flooding, Gillian and her family were at the **precontemplation/contemplation stages** - they did not have a plan to evacuate. Her family are now at the **action and maintenance stages** as they have a plan for how to evacuate Gillian using their wheelchair accessible vehicle. They purchased a generator to manage disruption to electricity when sheltering-in-place and they know how to use it. They are also actively sharing their experiences and knowledge with others to encourage their preparedness within their local community.

2. Engage an interactive discussion about functional capabilities and support needs in everyday life

The PCEP framework has 8 elements. Clients are prompted to think about their functional capabilities and support needs in each of these 8 areas. Not all areas will be relevant to each individual. The client should discuss what applies to them.

Functional Capabilities and Support Needs: Definitions

	Element	Prompt
	Communication	Getting, giving and understanding information.
	Management of Health	Taking care of your health.
	Assistive Technology	The help you get from equipment, but not people.
	Personal Support	Help you get from other people every day.
	Assistance Animals	Help from animals. How you care for them.
	Transportation	How you travel to where you want or need to go (e.g., car, bus, train, taxi, walking).
	Living Situation	Where you live and who you live with.
	Social Connectedness	The people you do things with. Your relationships with friends, family and other people. Help you give to other people.

When thinking about their functional capabilities and support needs, clients are encouraged to consider:

- what they do,
- where they do it,
- who they do it with, and
- their roles and responsibilities in everyday life – because emergencies can happen anywhere at any time.

Key point: Facilitate conversations about what people do in everyday activities as a starting point for understanding their valued choices, their functional capabilities, and how they manage their support needs in everyday life.

PCEP Framework: Functional Capabilities and Support Needs



Functional Capabilities and Support Needs: Probing questions



Communication

The process of getting and giving information by speaking, writing or using some other medium (e.g., sign language; picture exchange; voice output device). It includes the use of Augmentative and Alternative Communication (AAC)*. It is also the means of sending or receiving information such as telephone (landline; mobile) or computers.

* AAC are communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language.

- How do I communicate with others? Seeing
- How do I go about getting information? Hearing/hearing aids
- Who helps me? Speaking/output devices
- What assistive devices/technologies do I use to communicate? Understanding English/local languages
- What device do I use to call people or get information from others? Landline, mobile, computer, other device. Mobile or landline
- Who/what sources do I trust to give me helpful information? Computer/Tablet
 Interpreter



Management of Health

The medical management of your condition which may include medicines, nutritional, or health treatment. Medical management includes: management of wounds, catheters or ostomies; access to medical supplies, equipment or their maintenance; operating power-dependent equipment to sustain life.

- Where do I keep my health information? (e.g., identification, Medicare, health records) Medicare/identification/health records
- Have I registered for MyGov? (<https://my.gov.au>) Name of General Practitioner
- Have I registered for MyHealthRecord? (<https://myhealthrecord.gov.au>) Centrelink Information
- What are my health conditions/nutrition needs? Medications (including if assistance needed to administer medication/where stored/side effects)
- How do I manage and monitor my health/medical/treatment? Immunisation/Vaccination records
- What power sources are needed to operate equipment? Next of kin details registered if I am on my own at local hospital
- Who helps me? Advanced Care Directive
- Where do I get my supplies? Eating/swallowing (e.g., PEG or G-tube)
- How do I manage my supplies? Fluid intake or restrictions
 Special diet
 Home dialysis – peritoneal or hemodialysis supplies; clinic visits

- Equipment that requires power supply
- Refrigeration of supplies
- Sterilisation Care (e.g., wound, catheters, ostomy)
- Skin/hair or nail care
- Air alternating mattresses to maintain skin condition
- Contenance aids and supplies
- Medication Assistance (e.g., Syringe drivers)
- CPAP machine
- Home oxygen
- Central line (e.g., port; catheter) – regular flushing or med administration/infusions
- Allergies (e.g., medications, management)
- Other body functions (e.g., tracheostomy; autonomic dysreflexia)
- Other equipment that you must have with you



Assistive Technology

Assistive technology is any device, system or design, that allows you to perform a task that you would otherwise be unable to do. Assistive technology can increase safety or make tasks easier to do. It can include anything (e.g., tool or device; high or low tech) that assists you to carry-out daily activities.

- **What assistive devices, technology, or equipment do I use?** Mobility ADL devices/aids (e.g., wheelchair; walker; scooter)
- **What supplies do I always have on hand?** Self-care/personal care devices/aids
- **What power sources are needed to operate equipment?** transfer equipment
- **What is required to maintain the equipment?** modifications
- **Who helps me?** personal alarm
- **How do I direct my care?** other technology
- personal smoke alarm



Personal Support

The assistance received from another person for personal care or support with activities of daily living. It can include both practical and emotional support that enables you to do the things you want, need or have to do every day.

- Who helps me with my self-care/activities of daily living?
 - Are they formal/paid provider(s) or informal/unpaid support?
 - What do they help with?
 - When do they help?
 - How do I organise my personal care?
 - How do I manage if/when they are unavailable?
- Personal care
 - Daily activities at home; outside of home (e.g., help with self-care/personal care; meal preparation; house cleaning; home maintenance)
 - cultural/religious
 - medication supports
 - supervision
 - calls/check-ins
 - 24/7 support
 - personal alarm
 - personal support workers as well as your own self-care and any family that supports/ participants – paid & unpaid carers



Assistance Animals

They provide an important service that helps some people to more fully participate in personal and public life activities with more confidence and independence (e.g., mobility guide; hearing assistance; diabetic, seizure alert or response; emotional support, etc.)

- What care does my service animal need?
 - Who helps me to provide that care?
 - Where do I get supplies for my animal?
 - How do I organise my animal care?
 - Key commands for my service animal are: _____
 - Others should be aware about: _____
- Food
 - Water
 - Exercise
 - Favourite toy/Bedding
 - Animal identification/health records/
 - Vaccination records
 - Work/rest/play schedule



Transportation

How you get around from one location to another and includes independent travel and travel with others (e.g., family, personal support, carers), including service animals.

- How do I get to my activities in the community? Own vehicle
- Who helps me? Taxi
- How do I organise my transportation? Public Transport
- Where do I need to go? (e.g., work, leisure, volunteering, shopping, etc.) Transport service
 Other:



Living Situation

Where you live and the context of your home situation including who you live with, the type of building, how long you have lived there, the accessibility, safety, security, and adequacy of the physical environment, and the geographic location.

- I live with: Private home
- My water source is: Rental home
- My heating source is: Housing commission
- I live in: [city/town/rural location] Shared accommodation (e.g., I live with family/friends/ housemates)
- I have a functioning smoke alarm?: Yes or No Residential care home
- I have a household evacuation plan?: Yes or no Independent living
- There are ___ levels in my home. Town or tank water
- If in an apartment, I live on the ___ floor. Gas or electricity
- I spend most of my time in: Assisted living
- How many exits do I have in my property? Respite care
- I have a place to go in event of evacuation?
- I have people to stay with?
- I have knowledge of the local emergency centre/shelter in my area?



Social Connectedness

The personal and professional relationships between you and the people in your community.

The personal (e.g., family, friend, neighbour) and professional (e.g., service provider, community leader) relationships among people. Relationships can vary in closeness (e.g., acquaintance vs. close friend), and can be with individuals that are similar in status or with individuals of varying status and power (Chandra et al., 2010, p. 21).

- **Who is in my circles of support?**
 - **Who do I count on?**
 - **Who counts on me?**
 - **What type of support do I give them?**
 - **What type of support do they give me?**
 - **What is the nature of the relationship?**
 - How long have I known them?
 - How often do we see each other?
 - Do they live near or far?
 - Direction of support – I help them, they help me, both
 - Closeness/connectedness (emotional)
 - Are you/they judgemental or disapproving?
 - Are you/they supportive or encouraging?
 - **Where can I go if I ever need support or a place to stay?**
- Family
 - Friends
 - Neighbours
 - Workmates/schoolmates
 - Community clubs/social organisations/ sport/group programs
 - Formal support services/ support organisations
 - Support type: emotional; informational; instrumental/ concrete help
 - Geographical closeness
-

3. (Re)Consider functional capabilities and support needs in the event of a home fire or natural hazard emergency

The PCEP encourages an **all hazards approach** to thinking about disaster risk and provides information on storms, floods, tsunamis, bushfire, heatwave, and house fires.

The Provider should:

- Encourage thinking about how the person would manage disruptions to critical infrastructure and community services and supports that they rely on every day.
- Discuss two scenarios:
 - shelter-in-place
 - evacuate to somewhere safe.
- Use the 5 steps to preparedness and associated emergency preparedness information to support and enable individual problem solving. This may take place over one or a series of interactive sessions.

The Provider needs to:

- learn about and use their knowledge about the local hazard context
- understand the 5 steps to preparedness
- consider community-based supports and resources for people with disability and chronic health conditions.

Collaboration supports providers and clients to learn together about the local hazard context and use their knowledge of local community resources to improve emergency preparedness before, during, and after a disaster.

Service providers can:

- relay information, share resources, and enable communication between the client and their networks.
- recognise areas where (self)advocacy may be required to enable access to needed emergency preparedness resources (e.g. obtaining smoke alarms for people who are deaf or hard of hearing).



Image: Client re-considers her support needs in a discussion about bushfire evacuation

Example of shared learning

Janice, Keith's Community Care Coordinator was reviewing step 2 with Keith - Make a Plan. They were talking about gathering important documents and discussing safe storage of them. Keith shared that he had already arranged for a copy of his will and other important documents to be stored with his solicitor. This was new learning for Janice.

Janice

Isn't it funny, you know, the more you have these conversations, the more you learn about things, because now, by you telling me that it doesn't cost anything for you - for [your solicitor] to hold these documents, we can pass that information on to our other people.

Keith

With my solicitor it doesn't cost. I don't know about all of them.

Janice

Might even be a minimal fee, but hey, it's still quite important. What a great idea.

Keith

Well, you know where they are safe there, you don't have to worry. You know?

Later at their team meetings, Janice and the other care coordinators shared what they learned from their clients about strategies people have used to plan ahead. This provided the service providers with an opportunity to expand their repertoire of ideas that can be shared in future conversations with other clients. It contributed to their own learning about emergency preparedness planning and stimulated further brainstorming within the health care team about emergency preparedness (for themselves and the clients they serve).



Image: A young woman and her disability support provider learn together about emergency preparedness actions they can take.

Key point: Support the client to think how a disaster might affect what they do every day. Remember that they may have different priorities than you about what is important to them in an emergency.

Five Steps to Emergency Preparedness: Client Examples

Steps	Example
1. Know your local hazard risk	
<p>If you live near a river or creek or in a heavily wooded area you need to talk to your local council or local emergency services about your risk</p>	<p>Yasmin is the wife and primary caregiver to Jason who has dementia. She is aware of their flood and bushfire risk. The creek at the front of their property regularly floods. When it does, it is not safe to use the road. They evacuate using a road at the back of their property. However, Yasmin also noted that the area behind her house is surrounded by bush. They have experienced a bushfire and their nearest neighbour lost their home about three years ago. She said she was very lucky that their property was saved.</p>
2. Make a plan	
<p>Plan now for what you will do in a house fire or natural hazard emergency situation. Think about what you need to shelter-in-place and what you would need with you if you had to evacuate unexpectedly.</p> <p>Get yourself organised. This can include things like making a list of the medications you take or protecting the things you can't replace such as backing up family photos on a USB.</p> <p>Put together an emergency kit. Start with items such as: passports, wills, driver's license, marriage/birth certificates, mortgage/property/insurance documents, prescriptions, medical histories, and backup or copy things that are precious to you (e.g., photos; videos).</p> <p>Stock up on things that you will need to get through three days at home without essential services</p> <p>Pack things you need to have with you if you have to leave home unexpectedly.</p> <p>Put everything together in a waterproof container. Store your emergency kit where it is easy to access. Keep copies of important documents in a location other than your home (e.g., in the cloud, solicitor, work, mobile phone, etc.)</p> <p>Write down your plan.</p>	<p>Jason a man with quadriplegia was able to identify his need to plan for medical – access to his prescriptions, and also assistive technology. He worked with his doctor to get his medical information updated in My Health Record so that it could be accessed from anywhere. Jason is currently in the process of seeking funding for a generator which he needs to power his:</p> <ul style="list-style-type: none">• electric bed• alternating air mattress• charge his wheelchair <p>when the power goes out.</p> <p>Jason was working with the community care coordinator to write funding letters for financial support.</p>

Steps

Example

Share your plan with others. Keep your plan in a safe place where it is easy to access.

Review or practice your plan annually or when your life circumstances change.

3. Get your Home ready

Make preparations to your home. This means doing practical things like cleaning gutters or making sure that you have an asset protection zone cleared around your home.

It can include simple things such as testing smoke alarms regularly or having a home emergency kit ready. So, if you do lose power or need to evacuate in a hurry – you will have the essential items that you will need. You can feel safe knowing you have those things that are important to you.

Yasmin can no longer manage the work required to make preparations to her home. A neighbour helps her by clearing the gutters, as well as removing branches, leaves and sticks from their garden. When he works on the house, he also involves Jeff in parts of each tasks that he can still do (e.g., holding the ladder, carrying tools, piling branches away from the house)

Maya collects dry sticks and fallen branches and makes a clearance about 100 meters from her home. In recent weeks, she has fallen while clearing brush, leaving her *“all bandaged up”* and *“recovering from the nasty fall.”* Sometimes she employs a man to cut back dry brush as far as he can to make a greater clearance around her house.

4. Be aware

Know where to find accurate and trusted information about a hazard event such as online through emergency management websites, local ABC radio, the Bureau of Meteorology website, or through trusted social media sources such as the State Emergency Services Facebook page or Twitter feed.

It is important to know how to access the information, use that information, and heed warnings when they are issued.

Neil watches weather reports on the television. If a natural hazard event occurred Neil would listen for updates from the news, as well as from his mother or support workers. He would also call his mum to share the warnings with her and discuss what to do.

5. Look out for each other

Be aware about checking on your neighbours, your family and friends. When an event happens, make sure they know what is developing and make sure they are taking appropriate steps to be safe.

Emergencies are scary. They are stressful. When you are stressed, it is hard to think clearly. To prepare, talk with others about emergencies. Share what you know and help others to prepare.

Whenever there is a heavy storm on the Mid-North Coast of NSW, Jason makes contact with a friend who also has a disability. He wants to make them aware and check that they are safe and know what to do. His friend lives in an area prone to flooding, where there is risk of being isolated from the flood waters.

Five Steps to Emergency Preparedness: Probing Questions

1. Know your local hazard risk

- What are the local hazard risks where I live, work, spend time (e.g., work; friends; family; community)?

Tip: Look at a map of your area and identify the natural hazard risks.

- What essential services do I rely on? How would disruptions to services affect me?
 - Water
 - Electricity/Gas
 - Telephone/mobile
 - Chemist
 - Grocery
 - Health/Community Services
 - Health/Community Clinics
 - Health Supplies
 - Personal Support Services
- What are my everyday roles and responsibilities (where I go, what I do, who I do it with)?
- How might different hazards affect me? (e.g., heatwave, storm, flood, bushfire, smoke or poor air quality)
- How will the hazard affect the services/supports that I receive/rely on from other people or businesses?
- How will my support needs change or be heightened in an emergency?

Tip: don't forget how your animals might be affected (pets, farm animals, or assistance animals).

Where I will go for more information

- I can contact my local council at: _____ to learn more about my hazard risk.
- I can get information from the following emergency service websites: _____

Tip: In NSW, you can look up your local risk by suburb or postal code here: <https://www.ses.nsw.gov.au/your-local-risk/>

2. Make a plan

- My functional capabilities are:
- My support needs are:
- Using the “capability wheel” of the PCEP, what would my needs be in the event of an emergency?

Tip: Think about which of the 8 areas are most important to my emergency planning (e.g., communication, management of health, assistive technology, personal support, assistance animals, transportation, living situation, social connectedness).

- Consider two scenarios: shelter-in-place (stay); evacuate to somewhere safe (go).
 - What will help me to shelter-in-place or evacuate?
 - Where will I go if I need to evacuate?
 - What will be a problem for me if I stay; if I evacuate?
- What will I need for an emergency kit for home (stay) and evacuation (go)?
 - What do I currently have?
 - What do I need to get and how will I get it?
- What can I organise now that will make it much easier on me and my family in an emergency?

Tip: Consider different scenarios:

- Roads are closed or blocked
- Power goes out
- It is the middle of the night
- My support worker is unable to get to me
- I am separated from family/carers

- Who else needs to be involved in my plan?
- How will I communicate my plan to others?
- Where will I write and store my emergency plan?
- Places I could go in an emergency are: (e.g., family; friends; accessible motel; community centre; etc.)

Examples of plans

Tip: You can download this *RediPlan document and use it to document your plan: <https://www.redcross.org.au/getmedia/9fc498a0-8221-4bcb-b7c6-6d482d448477/Your-RediPlan.pdf.aspx>

* This document also has the numbers you need to call for help in case of an emergency and helps you to get organised.

Carers of people with dementia can access a Guide to Using RediPlan: <http://dementiakt.com.au/resource/carers-ready-guide/>

Creating an emergency kit

Home (stay) Emergency Kit Contents

- A portable radio with spare batteries. List Channel for ABC radio: _____
- A torch with spare batteries
- A first aid kit
- Candles and waterproof matches
- Important documents including emergency contact numbers
- Copies of any emergency plans
- A waterproof bag for valuables
- I will add the following items to my Emergency (stay) kit: _____

Evacuation (go) Emergency Kit Contents

- Bottled water
- Dietary requirements
- Mobile phone, spare batteries and charger
- 3-day supply of medications (including prescriptions)
- 3-day supply of appropriate clothing and footwear
- Personal care items
- Blankets
- Spare home and car keys
- Cash and credit cards
- Food and medications for your pets
- I will add the following items to my Emergency (go) kit: _____

Getting things organised

- Protect the things you can't replace
- Write down your medical information
- Get and review insurance (home/property; vehicle; life insurance)
- Identify your next of kin
- Make a Will
- Appoint enduring Power of Attorney
- Appoint enduring Guardianship
- Make Advanced Care Directives
- Make a financial plan
- Plan for your pets/stock

Where I can go for more information

Additional emergency kit information can be found at:

- Storms: <https://www.ses.nsw.gov.au/disaster-tabs-header/storm/>
- Bush fires: <https://www.rfs.nsw.gov.au/resources/bush-fire-survival-plan>
- Heat wave: <http://www.health.nsw.gov.au/environment/beattheheat/Pages/prepare-for-heat.aspx>

3. Get your Home ready

- What can I do for myself to protect my home?
- What do I need help with?
- How will I get that help?

Ways I can reduce home damage

- Keep gutters and downpipes clear of leaf litter
- Trim trees and cut back overhanging branches
- Ensure my roof is in good repair
- Maintain yard and store flammable liquids and woodpiles away from the house
- Keep grass and shrubs trimmed
- Install and maintain smoke alarms in hallways, bedrooms and living spaces. Install fire blankets and extinguishers near kitchen doorways
- Ensure my insurance policy is current and takes into account likely disasters in my area

Where I can go for more information:

- Bushfire household assessment tool
<https://assessmyrisk.rfs.nsw.gov.au/>
- Smoke alarms (buying, installing, maintaining)
<https://www.fire.nsw.gov.au/page.php?id=80>
- Smoke alarms for the deaf and hearing impaired
<https://www.fire.nsw.gov.au/page.php?id=629>
- Using fire safety equipment
<https://www.fire.nsw.gov.au/page.php?id=9221>
- Using sandbags for a flood
<https://www.ses.nsw.gov.au/floodsafe/prepare-your-home/during-a-flood/using-sandbags-to-protect-your-home/>

4. Be Aware

- Where will I get information about natural hazard events in my area?
- Who can I contact if I need more information?
- What is the trigger for me to make the decision to leave?
- What is the trigger for me to make the decision to shelter-in-place?
- Do I have the capability to stay and defend my home?
- If a warning has been issued, what will I need help with? How will I get that help?

Sources of warning information about a natural disaster

- Emergency broadcasters on local radio and television (e.g., ABC)
- Online news from reputable sources (e.g., ABC online)
- Bureau of Meteorology
- Neighbours and other people in the community
- Elders or other community leaders
- Social media sites such as Facebook and Twitter – particularly those that belong to emergency services organisations
- Emergency alert message to your mobile phone or landline
- Natural warning signs such as clouds, smoke rising or receding water.

Actions I can take before and during a disaster

If a disaster is imminent in my area, I should listen to the local ABC radio or monitor other media (emergency services Facebook, Twitter, etc.) for updates and advice.

Tip: If you have a mobile phone and coverage is in place, warnings may be issued by the SMS alert system.

It is best to make a safe and informed decision early to avoid having to be rescued later.

If a warning has been issued, I should:

- Activate my emergency plan
- Remove flammable items from decks and verandas (boxes, furniture, doormats)
- Secure outdoor items that can blow around in strong winds
- Ensure my emergency kit is ready to go in case I lose power or need to leave in a hurry
- Park vehicles under solid shelter away from trees and power lines
- Follow all advice and instructions given to me by emergency services.

It is best to leave well before roads and evacuation routes are cut off or closed.

If an evacuation order is issued:

- Turn off electricity and gas at the mains before I leave
- Turn off and secure any gas bottles
- Take my emergency kit
- Take my pets with me
- Keep listening to local radio for information, updates, advice
- Follow all instructions given by emergency services

Tip: Information on preparing a fire escape plan can be found at:

<https://www.fire.nsw.gov.au/page.php?id=883>

To create my own fire escape plan: <https://www.fire.nsw.gov.au/page.php?id=292>

Where I can go for more information:

- Bush fire: <http://www.abc.net.au/news/emergency/plan-for-an-emergency/bushfire/>
- Storm: <http://www.abc.net.au/news/emergency/plan-for-an-emergency/storm/>
- Flood: <http://www.abc.net.au/news/emergency/plan-for-an-emergency/flood/>

Mobile Emergency Preparedness Applications

Application	Description	
 Emergency+	Provides links to emergency and non-emergency services, such as 000, state emergency services, and police. In an emergency, the app establishes your precise location and forwards your information to the appropriate organisation.	http://emergencyapp.triplezero.gov.au
 Get Prepared	Provides information and tools to create, complete, and share your personalised emergency plan and include key contacts.	www.redcross.org.au/get-help/emergencies/preparing-for-emergencies/get-prepared-app
 Ready Steady Safe	Promoting children's preparation for emergencies and hazards through games and interactive planning.	iPhone: itunes.apple.com/au/app/ready-steady-safe/id1281404601
 My Fire Plan	Provides information and tools to create, complete, and share your personalized bush fire survival plan for you, your family, and your home.	iPhone: https://itunes.apple.com/au/app/myfireplan/id726634175?mt=8
 Live Traffic	Live updates on traffic incidents and conditions, along with personalised alerts, on NSW roads.	www.livetraffic.com/desktop.html
 Fires Near Me NSW	Presents information on current bushfires incidents, emergency warnings, and total fire ban locations across NSW.	www.rfs.nsw.gov.au/news-and-media/stay-up-to-date

Application	Description	iPhone: itunes.apple.com/au/app/ses-floodsafe/id558325156
 FloodSafe	Local flood information, and information on preparing for and staying safe during and after storms.	iPhone: itunes.apple.com/au/app/ses-floodsafe/id558325156
 StormSafe	Local storm information, and information on preparing for and staying safe during and after floods.	iPhone: itunes.apple.com/au/app/ses-stormsafe/id562164182

5. Look out for each other

- How will I think, feel, and act in an emergency situation?
- What key contact information should I have handy? Why/how will I use those contact details in an emergency?
- Who will I rely on in a disaster? What do I rely on them for (e.g., physical, emotional, practical support)?
- Who will rely upon me in a disaster? What do they rely on me for (e.g., physical, emotional, practical support)?
- Have I communicated my plan with them?
- Do they have a plan? Have they communicated it with me/others?
- How will I keep myself emotionally and physically safe while helping others?
- My key contacts are:

- The people I will contact in an emergency are:

- The people who will contact me are:

Managing emotions and preparing communities

- Consider how you might manage your emotions and support others.
- Talk with others about emergencies. Share what you know and help others to prepare.
- Expand your network – get to know your neighbours.

Where I can go for more information:

- Lifeline Australia. Recovering after a natural disaster website has toolkits and resources at this web address: <https://www.lifeline.org.au/get-help/topics/recovering-after-a-natural-disaster>



Image: Wheelchair ramp, accessible van, and other assistive technology

4. Communicate the plan

Conversations about emergency preparedness can support people to take incremental steps toward their own preparedness. These planning conversations help people to make good decisions and take more effective action when an emergency happens.

People should be enabled to:

- Make a verbal plan
- Document their plan
- Share their plan with others

This PCEP user guide supports a menu of resources. Individuals can choose from these options to document their learning, reflections, and action plans, rather than creating one static emergency plan document.

Other options can include:

- the service provider taking notes and documenting decisions for their records and giving a copy to the client to enable conversations with their support network.
- the client and provider agreeing on one or more actions they will each take prior to the next community visit.
- the client taking full responsibility for their planning decisions and actions in collaboration with their family, carers, or friends.



Image: Disability support coordinator and client communicating about preparedness actions they will take

Key point: Remember to involve the person's informal support network. Together they should discuss how they will plan and act together in an emergency. Gaps in an individual's support network can provide direction for enabling preparedness through formal support and advocacy.

Advocacy Role of Providers

When an individual's preparedness needs do not match the level of support available to them, advocacy may be needed.

Comprehensive information, gathered through the PCEP process tool and framework, can be shared with managers to assist them in their review of organisational preparedness and business continuity plans to better support duty of care to clients.

Managers can use this information to review and address shortfalls in emergency preparedness across the diversity of clients they serve. This can help them to plan for and develop better services, supports and advocacy within their organisation and in their local community.

Community-based health care and disability support agencies are optimally placed to support client advocacy by:

- providing education to others about the functional capabilities and support needs of people with disability in an emergency situation.
- using their knowledge of local resources and working with others in the community to assist clients to develop their stay or go plans.
- advocating on behalf of the client for needed resources to enable greater self-sufficiency in an emergency.
- raising awareness within the local community about disability inclusive disaster risk reduction
- working together with local emergency managers and in cooperation with government, non-government, local business and community organisations to engage the whole community in problem solving together to increase the resilience to disaster triggered by natural hazard events.



Image: Icon indicating accessible parking

Key point: PCEP should involve a series of conversations that are revisited, regularly and over time. This is because people and their contexts change and, so too, will their emergency preparedness decisions.

Helpful Tips: Facilitating Conversations about Emergency Preparedness

* Tips	Examples
Take advantage of naturally occurring opportunities to start the conversation	Refer to natural hazard events appearing on the news. <i>“Did you hear about the [hazard event] in [area]. It made me think about what I would do if that happened. Have you experienced that before, or know what you would do?”</i>
Speak about the same concept across different situations. Gradually expand the topic	In her first meeting with Meredith, Margaret thought about and discussed what she would need consider to shelter-in-place at home. Meredith then asked Margaret to consider what she would need to take if she had to evacuate to somewhere safe.
Use concrete examples and language to assist understanding	Neil’s support worker referred to specific times of the day when discussing his preparedness. <i>“Let’s talk about if a storm occurred in the middle of the night when you are in bed asleep.”</i>
Don’t explain everything at one time. Offer information in small pieces so that it isn’t overwhelming	Maya had not considered what she would do if there was a bushfire. In their first conversation, it was clear to her care coordinator that Maya needed more time to think about bushfire and how it could affect her. The care coordinator planned to revisit the conversation on her next visit and to gradually introduce preparedness into conversations in future visits.
Do not direct the conversation, instead facilitate	Carolyn used open ended questions when talking with Jason about his medical needs. This helped Jason to brainstorm how he might access his prescriptions if he could not access the usual Chemist who has his prescription on file.
Revisit the conversation regularly	When Janice was having a conversation with Keith and his wife, they realised that the emergency contact that they had previously identified in Keith’s plan (nearly 6 months ago) had moved interstate.
Use questions to check for understanding	Janice asked Keith what was most important to him if he had to evacuate. Keith identified family photos as one of the most important items. Janice followed up with questions about whether Keith knew how to back up family photos on a USB and they discussed placing that in his emergency kit. When Janice asked about important documents, Keith clarified that he had already arranged for his will to be stored with his solicitor.
Set up situations so the person can involve their key support networks in the conversation	Arienne asked Judy if she would like her daughter with her during the conversation about emergency preparedness. Judy appreciated this, as her daughter was a primary person she wanted to identify in her plan. Her daughter’s involvement helped to begin the conversations and extend discussion about what the whole extended family would do in an emergency.

* Tips

Examples

Encourage active engagement in the topic by providing tools and resources to learn more

Meredith gave Margaret a document with probing questions about preparedness in each of the 8 functional areas. Margaret was able to review this between visits. On the next home visit, Meredith and Margaret were able to have a more detailed conversation about Margaret's evacuation plan.

Recommend mobile applications for people to learn more about preparedness.

Encourage people to take this readiness quiz to get them thinking about emergency preparedness: <https://redcross.getfeedback.com/r/04KsmGie/>. Individuals can take the quiz and learn one simple thing they can do to get ready.

Encourage people to think about their household preparedness. This survey provides a sequence of steps in preparing your home: <http://www.seshomeemergencyplan.com.au/>

Provide helpful information from trusted sources for the person to follow up in their own time

Show clients the NSW SES Facebook Page and Emergency Services websites.

*Helpful Tips were inspired by Stancliffe, R., Weise, M. Dying to Talk Project, Sydney, Australia



Image: Woman on verandah with rural scene in background

Seven Things to Remember

7 things this tool helps you to do:

Recognise people's stage of emergency preparedness.

Learn about what people do, who they do it with, and what is important to them.

Enable people to identify their capabilities and support needs in 8 functional areas.

Learn together with others about natural hazards and what impact they can have.

Identify the specific support needs people will have in an emergency and anticipate challenges during and after an emergency.

Know the 5 steps to preparedness and enable people to take those steps together with their support network.

Identify the things that stop people from preparing, responding, and recovering effectively from emergencies.

7 things you need do to use this tool well:

Appreciate emergency preparedness as a process and understand that people may be at different stages in their preparedness. Have regular conversations about preparedness.

Listen to people and value them as capable partners in planning, developing, and monitoring their emergency preparedness process.

Recognise that everybody has capabilities and support needs every day. Enable people to share what is unique to them.

Understand that we all have local knowledge that is relevant to emergency preparedness. This includes knowledge about local natural hazards; knowledge about community services and supports; knowledge about the people and resources in the local community.

Collaborate with others to use local knowledge in creative ways that mobilise resources and increase supports needed in an emergency.

Provide people and their support networks with information, tools, and resources that they can use to make decisions and take preparedness actions together.

Apply knowledge and skills in advocacy and enable self-advocacy in others in order to remove the barriers for people before, during, and after an emergency

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Person-Centred Emergency Preparedness (PCEP) Framework: Functional Capabilities and Support Needs



My Emergency Preparedness Profile

My level of preparedness is:



My functional capabilities in an emergency are:

- Communication
- Management of health
- Assistive technology
- Personal support
- Assistance animals
- Transportation
- Living situation
- Social connectedness

Specific things I can do for myself to prepare, respond, and recover are:

My support needs in an emergency are:

- Communication
- Management of health
- Assistive technology
- Personal support
- Assistance animals
- Transportation
- Living situation
- Social connectedness

Specific things I need support or advocacy to prepare, respond, and recover are:

Preparedness actions I will take are:	Things I will do for myself:	Things I need support for:
<input type="checkbox"/> Learn about my local hazard risks	_____	_____
<input type="checkbox"/> Prepare for disruptions to essential services that I rely on	_____	_____
<input type="checkbox"/> Organise important documents and the things that are precious to me	_____	_____
<input type="checkbox"/> Prepare my emergency (stay/go) kit	_____	_____
<input type="checkbox"/> Protect my home and property	_____	_____
<input type="checkbox"/> Know where to look for hazard information and warnings	_____	_____
<input type="checkbox"/> Plan for what will trigger my decision to shelter in place or evacuate	_____	_____
<input type="checkbox"/> Communicate my plan with people that I rely on and people who rely on me	_____	_____

Notes

I will review my preparedness profile on (date): _____

PREPARE NSW (2017 – 2018): CO-DESIGNING RESOURCES FOR COMMUNITY HEALTH AND DISABILITY SUPPORT PROVIDERS ON PERSON-CENTRED EMERGENCY PREPAREDNESS.

Citation: Villeneuve, M., Sterman, J., & Llewellyn, G.L. (2018). *Person-Centred Emergency Preparedness: A process tool and framework for enabling disaster preparedness with people with chronic health conditions and disability*. Centre for Disability, Research and Policy, University of Sydney, NSW 2006.

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Further Information: <http://sydney.edu.au/health-sciences/cdrp/projects/PREPARE-NSW.shtml>