

painaustralia

TALKING ABOUT PAIN

LANGUAGE GUIDELINES FOR CHRONIC PAIN

2019



The purpose of these Guidelines is to promote the consistent use of appropriate, inclusive and non-stigmatising language when talking or writing about chronic and persistent pain and people living with these pain conditions.

This resource was developed after broad consultation with Painaustralia members. A particular thanks to our consumer networks who provided extensive input and the specific input from our dedicated Consumer Advisory Group who reviewed the guidelines. Also special thanks to Prof Lorimer Moseley who provided important insights.

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Why do we need guidelines?

Words are important. The language we use and the stories we tell have great significance to those involved. They may carry a sense of hope and possibility or be associated with a sense of pessimism and low expectations – both of which can influence a person's outcomes.¹

This means the words used to talk or write about chronic and persistent pain can have a significant impact on how people living with chronic and persistent pain are viewed and treated in our community.²

It's important to recognise that the words used in speech and writing can influence others' mood, self-esteem, and feelings of happiness or depression, in fact, the words we use can influence pain itself.³

The use of language can not only affect the person with pain but their family, friends, carers and wider society as well – which may increase stereotypes, stigma and discrimination.

Appropriate language must be

Empowering The terms we use and the conversations we have should emphasise enablement and empowerment, giving people with persistent pain mastery over their situation, not implying theirs is a problem that only others can solve. It is important to use language that focuses on the abilities (not deficits) of people living with chronic and persistent pain to help people stay positively and meaningfully engaged and retain feelings of self-worth.

Accurate Talking about persistent pain using outdated or incorrect terms, diagnoses or hearsay, can be offensive and, critically, makes the problem worse. Be accurate and where possible precise. It is important to avoid talking about someone's pain in terms of an injury.

Respectful Respectful language recognises that chronic and persistent pain is not the defining aspect of anyone's life. It is important to respect others' preferences in words used about them. It is important to remember that chronic and persistent pain can affect anyone, at any age and is something everyone experiences differently.

Inclusive People with persistent pain are a part of many communities, and there are many within our networks silently living with chronic pain. Be mindful of not reinforcing stereotypes or myths about chronic and persistent pain.

Don't be afraid to ask

Individuals and families will express their experiences of chronic and persistent pain in ways that has meaning and significance to them. This means that not everyone will wish to have their experiences with chronic and persistent pain described in the same way.

Where possible, ask that person directly if they have an issue with any of the below words or any others that may be relevant.

When talking about people with chronic and persistent pain

What to say	What not to say
A person/people with chronic or persistent pain	Sufferer
A person/people living with chronic or persistent pain	Victim
A person/people with a diagnosis of chronic or persistent pain	Afflicted
Remember to avoid labelling⁴	Patient (when used outside the medical context)
Conditions describe what a person has, not what a person is.	Subject
Conditions, not people, are monitored.	'They' (talking about all people with chronic and persistent pain rather than the individual)
People are not unsuitable for treatments: treatments are unsuitable for them.	
People have conditions; they don't suffer from them	

When talking about a carer, family member or friend of a person with chronic and persistent pain

It is not accurate to describe them as 'living with persistent pain' themselves. Instead, use 'living alongside, or caring for, supporting etc.

This is important because only a person with chronic and persistent pain can truly understand what it is like to live with chronic and persistent pain. Similarly, only a carer knows what it is like to care for a person with chronic and persistent pain.

It is important when referring to someone else in a caring role that you use terms that are emotionally neutral.

Everyone has a different experience as a carer and using terms such as 'burden' assumes the role is entirely negative, or that caring for the person with chronic and persistent pain is difficult.

Emotionally neutral terms do not make assumptions that the role of the carer is either negative or positive.

Things to remember when talking about chronic or persistent pain

Appropriate language is a vital component in communicating a sense of self-determination because feeling powerless can be overwhelming, especially when decisions seem to be, or are, in the hands of others.⁵

The **preferred** terms when talking about the impacts of chronic and persistent pain are:

- Disabling
- Challenging
- Life-changing
- Stressful

The following terms **should not** be used:

- Hopeless
- Unbearable
- Impossible
- Tragic
- Devastating

References

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5. Mental Health Coordinating Council (2018) 'Second Edition: Recovery Oriented Language Guide'. Access online here: http://www.mhcc.org.au/wp-content/uploads/2018/05/Recovery-Oriented-Language-Guide_2018ed_v3_201800418-FINAL.pdf

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