
painaustralia

CHRONIC PAIN
LANGUAGE GUIDELINES

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DRAFT

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

Why do we need guidelines?

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

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

The difficulty in talking about painful sensations forces people to draw on metaphors, analogies and metonymies when attempting to communicate their pain to others.³

It's important to recognise though that the words used in speech and in writing can influence others' mood, self-esteem, and feelings of happiness or depression.⁴ A casual misuse of words or the use of words with negative connotations when talking about chronic pain in everyday conversations can have a profound impact on the person with chronic pain, as well as on their family and friends. It can also influence how others think about chronic pain and increase the likelihood of a person with chronic pain experiencing stigma or discrimination.

Language is important both because of what it communicates and in how many ways it does it. It conveys the important rules about how we, and the others in our environment (seen and unseen), expect ourselves to go about our lives. The power and impact of language are really paradoxical in how language can influence behaviour.⁵

Appropriate language must be:

- Accurate
- Respectful
- Inclusive
- Empowering
- Non stigmatising

Everyone deserves respect

Respectful language recognises that chronic pain is not the defining aspect for anyone's life. It is important to respect others preferences about words used about them, regardless of whether the person being talked about is present or not.

Be mindful of not reinforcing stereotypes or myths about chronic pain.

It is important to know the facts about chronic pain. For example, it can affect anyone at any age and for a range of reasons. It can have a serious and legitimate impact on a person's ability to work, exercise and socialise.

Talking about chronic pain in a negative manner or by using incorrect terminology or inaccurate facts can reinforce stereotypes and further exacerbate the myths and misinformation about chronic pain.⁶

Everyone's experience of living with chronic pain is unique, as there are many different types of chronic pain and symptoms that may present differently in different people.

Don't be afraid to ask

Individuals and families will express their experiences of chronic pain in ways that has meaning and significance to them. Not everyone will wish to have their experiences with chronic pain described in the same way. Where possible, ask that person directly. We can respect the dignity of each individual by respecting that person's wishes regarding use or non-use of certain terms relating to chronic pain.

Empowering language

It is important to use language that focuses on the abilities (not deficits) of people living with chronic pain to help people stay positively and meaningfully engaged and retain feelings of self-worth.

When talking about people with chronic pain

It is important to avoid labelling people. Conditions describe what a person has, not what a person is. Diseases are treated, not people. Diseases, not people, respond to treatment. Conditions, not people, are monitored. People are not unsuitable for treatments: treatments are unsuitable for them. People have diseases, they don't suffer from them.⁷

People with chronic pain are individuals first and their diagnosis should not be regarded or referred to as the defining aspect of their life.

The following terms/phrases are preferred when talking about a person with chronic pain:

- A person/people with chronic pain
- A person/people living with chronic pain
- A person/people with a diagnosis of chronic pain

The following terms/phrases should not be used:

- Sufferer
- Victim
- Afflicted
- Patient (when used outside the medical context)
- Subject
- He/she's an attention seeker
- 'They' (talking about all people with chronic pain rather than the individual)

Why?

Many of the terms listed are demeaning and derogatory. Terms such as 'sufferer' and 'victim' contribute to the stigma surrounding chronic pain. Using the terms person/people with chronic pain or person/people living with chronic pain emphasises that they are a person first and does not place judgements on the individual because they have chronic pain.

Often people with chronic pain are referred to in a group as 'they' which loses sight of the individual and focuses on the condition, using the preferred terms avoids this situation.

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

People with chronic pain have indicated that they would prefer the term person/people living with chronic pain to be used by or to refer to a person diagnosed with chronic pain rather than used to refer to family, carers and friends.

It is preferred that carers, family and friends are referred to as:

- Living alongside (someone/a person/my partner/my mother etc) who has chronic pain
- Living with/caring for/supporting a person who has chronic pain
- Living with/caring for/supporting a person with a diagnosis of chronic pain
- Living with the impact of chronic pain

When describing someone who is caring for a person with chronic pain the preferred terms/phrases are:

- Family member(s)
- Person supporting someone living with chronic pain
- Wife/husband/partner
- Child/Son/Daughter
- Parent
- Friend
- Carer or care-giver – not everyone will like to be referred to as a carer. If possible, ask what the person's preference is before using this term.

In this context the terms apply to someone that is providing unpaid care to a person with chronic pain, which is different to a professional or paid carer. When describing the impact of the caring role on someone providing care for a person with chronic pain the preferred terms are:

- Impact of supporting (someone/a person/my partner/my mother etc) with chronic pain
- Effect of supporting (someone/a person/my partner/my mother etc) with chronic pain

The following terms should not be used when describing the impact of the caring role on someone providing care for a person with chronic pain:

- Carer burden
- Burden of caring

Why?

Only a person with chronic pain can truly understand what it is like to live with chronic pain. Similarly, only a carer knows what it is like to care for a person with chronic 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 pain is difficult. Emotionally neutral terms do not make assumptions that the role of the carer is either negative or positive. Of course, it is acceptable for a carer to talk about the difficulties they may experience as a result of providing care.

When talking about the impacts of chronic pain on the person living with chronic pain

Appropriate language is a vital component in communicating a sense of self-determination, because feeling powerlessness can be overwhelming, especially when decisions seem to be or are in the hands of others.⁸

It is also important to remember that the symptoms of chronic pain will be different for each individual, depending on the cause of the chronic pain and the possible progression of the condition. It will therefore impact upon people's lives in different ways, of which not all may be negative.

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

- Disabling
- Challenging
- Life-changing
- Stressful

The following terms should not be used:

- Hopeless
- Unbearable
- Impossible
- Tragic
- Devastating

Why?

Each person will relate differently at different times to their diagnosis and how chronic pain impacts their life will vary from one person to another. While it is important to be truthful and realistic about the impact of chronic pain, the words used do not need to be negative, disempowering, pessimistic or frightening.

REFERENCES

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