



Chronic Pain AUSTRALIA

National Pain Survey 2020

Faces of pain



National Pain Week 2020

#NPW2020



Chronic Pain
AUSTRALIA

National Pain Survey 2020

Answers reported by key themes and metrics

Total number of survey respondents - 1217

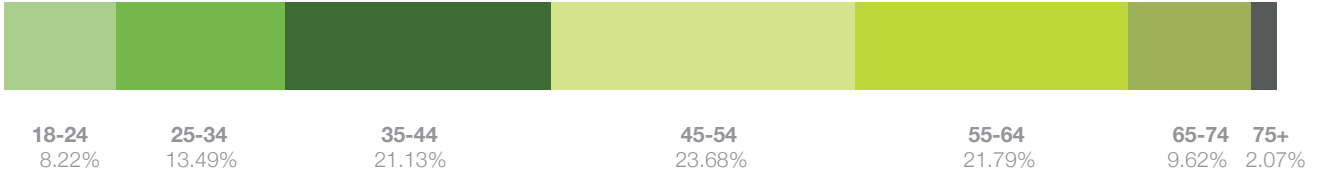
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DEMOGRAPHICS

Total number of survey respondents - 1217

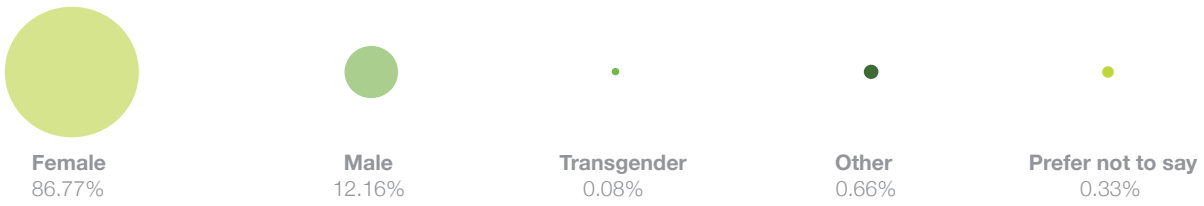
Question 1

What is your age?



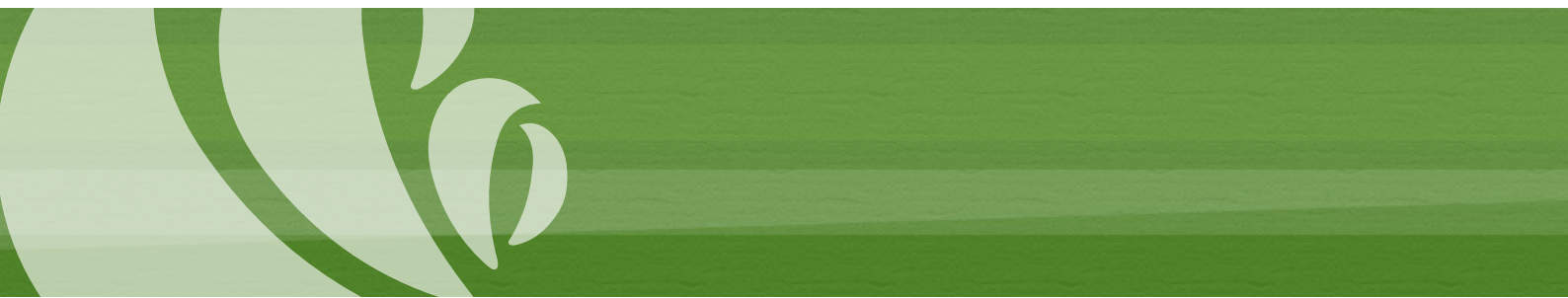
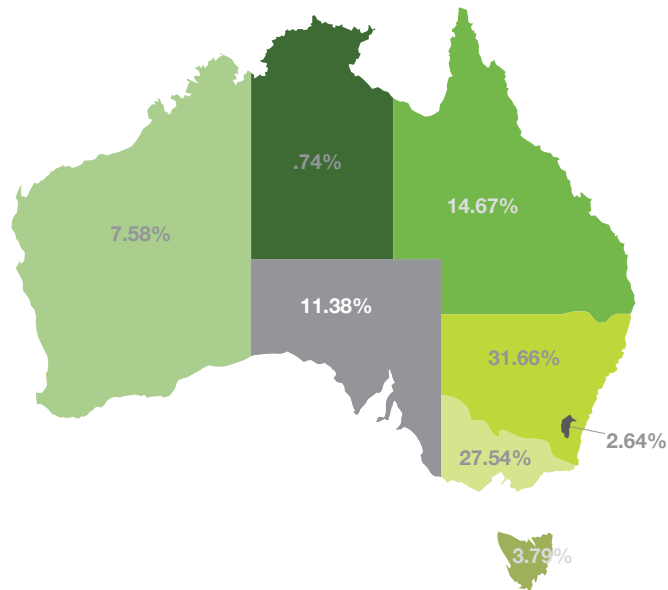
Question 2

What is your gender?



Question 3

What state do you live in?



GENERAL PRACTITIONERS

Question 4

How often do you visit your GP about your chronic pain?



Question 5

On a scale of 1-10 how well do you think your GP manages your chronic pain?

5/10
Average

Question 6

What are the most important things for GPs to know, understand and do when treating someone living with chronic pain?

- **We are not one size fits all**

- Further educate themselves about different conditions they might not know much about
- Please just believe us when we say we are in pain
- The experience of ongoing pain is not just due to biological factors but also psychosocial factors and therefore needs a wider treatment plan

- **Pain is real, debilitating and exhausting**

- Put me in touch with other resources and pain management options not just medication
- Listen to me – don't make assumptions about me or my pain
- My pain doesn't stop – just because I am walking today and seem fine doesn't mean that I will be walking well after the appointment or the next day

- **We are not all drug seekers**

- Just because we try to function normally day-to-day doesn't mean we are pain free
- Understand that we don't like using strong pain medication but sometimes it is necessary to assist us live a somewhat productive and worthwhile life
- Know when, how and to who you can refer me to, to better manage my pain

- **Pain affects all areas of our health and lives**

- Have some compassion and treat me like a real person with emotions and feelings
- Sometimes I become so used to my pain that I don't realise I am in pain even though my body is hurting
- Understand that I am in pain – not a hypochondriac

- **Living with chronic pain can be isolating and depressing**

- Ask how I am managing the pain and work with me, not against me
- Have an open mind – the client is the expert in their condition and their body
- Don't judge or stigmatise me

Question 6 (continued)

- **My pain isn't just all in my head – I am not making this up**
 - Understand and tell me about the side-effects of my pain medication
 - They need to know the limits of their knowledge and admit that – help me find alternative health professionals to help me or work with me to explore what the pain could be
 - It's ok to say you don't know how to treat my pain. Keep helping me manage it with medication and non-medication methods
- **Listen, acknowledge and respond**
 - Understand that the injury has healed and the pain is a separate problem from the injury
 - My pain levels go up and down but the pain is always there
 - After living with pain for so long, many of us know what does and doesn't work for us, take our experience and suggestions onboard.
- **Understand that we have been conditioned to expect no medical professional will believe us**

Question 7

If there was one thing your GP could do now to help you manage your chronic pain, what would it be?

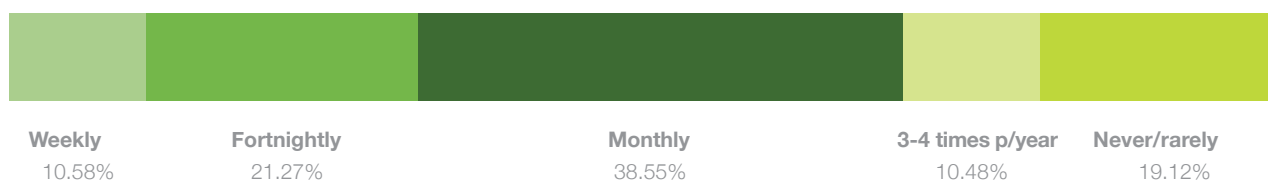
- **Believe me and my pain (50% of respondents)**
 - Keep on championing my rights
 - Understand my condition
 - Provide referrals to other practitioners who can help me manage my pain
 - Let me have pain medication for the times I need it
- **Prescribe medicinal cannabis (25% of respondents)**
 - Be better educated about chronic pain
 - Empathise
 - Take time to consult with me instead of the 6 minutes of your time I am given per visit
- **More investigation into what is causing my pain and continue until the cause is known**
 - I don't know/Nothing
 - My GP does an excellent job managing my pain
 - Consider my whole body don't just focus on my pain when treating me
 - Continue my sessions using telehealth
 - Look at a holistic approach to managing my pain
 - Coordinate my care and link in with the other health professionals I see
 - My GP is managing my pain levels as well as possible. My GP refers me appropriately when necessary and collaborates with my other specialists



PHARMACIST

Question 8

How often do you visit your pharmacist about your chronic pain?



Question 9

On a scale of 1-10, how well do you think your pharmacist manages your chronic pain?

4/10
Average

Question 10

What are the most important things pharmacists should know, understand and do when treating someone living with chronic pain?

- **I am not a drug seeker**

- Don't treat me with suspicion
- Do not shame me for needing S8 drugs
- Don't judge me
- Believe me and my pain
- Don't interrogate me about my medications

- **Don't discuss my medication needs in front of other customers**

- My pharmacist is great
- Don't assume what I'm saying isn't true or that the medication I have been prescribed is wrong for me
- Understand what it's like for me to live with chronic pain
- Be familiar with my medication history
- Better education about the different types of pain conditions

- **Listen to me and my needs and take me seriously**

- I don't use a pharmacist for my pain management at all
- Know and advise me on the side-effects of my medication
- If we are grumpy, it is because of the pain – not because of them
- Create a friendly working relationship with me
- Have empathy and an open mind
- I see pharmacists as providing medication only – they don't have a role in managing my chronic pain

- **Explain to me in plain English how my medication works**

- Consider what other medication I am taking
- Fully explain the pain relief available whether it be prescription or over the counter
- Just because I have a prescription to a medication which can become addictive doesn't mean I am addicted

Question 10 (continued)

- Just because someone looks healthy doesn't mean they're ok
- My GP has prescribed my medication for a reason
- My pharmacist is amazing!

- **When you treat me suspiciously it creates tension between us which exacerbates my pain and does nothing for our pharmacist-patient relationship**

Question 11

If there was one thing your Pharmacist could do now to help with your chronic pain, what would it be?

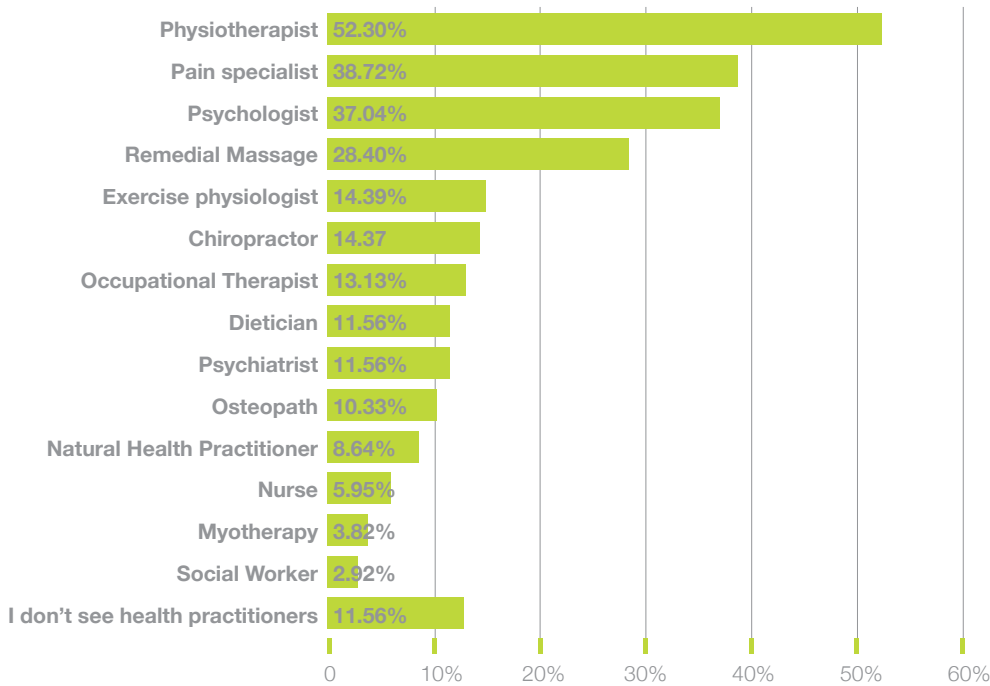
- Be understanding and helpful
- Don't question me about why my GP has changed my medication – I don't always know
- Be more sympathetic than sceptical
- Listen with empathy
- **Don't make me feel guilty when getting my prescription medication – offer me genuine solutions instead**
 - Help me get on medicinal cannabis
 - Understand what it is like for me to live with chronic pain
 - Help me understand what my non-medicine treatment options are
- **Look at the person not just the pain – I am more than my pain**
 - Ensure that I know about the side-effects of my medications
 - My pharmacist is great – they are doing all they can to help me
 - Nothing, because I don't think my pharmacist knows what my condition is
 - Take a non-judgemental approach to me
 - Make sure my medication is in stock
- **Stop being so judgemental and putting everyone into one category. Understand that I can have the same illness as someone, but our symptoms can be completely different**
 - Be more supportive and less judgemental
 - Nothing – the pharmacist's role is to dispense my medication, that's it.
 - Advertise how they can help – I didn't realise they could
 - Be able to deliver my medication to me for the days my pain is so bad I can't leave home



OTHER HEALTH PROFESSIONALS

Question 12

What other health professionals do you see to help you treat chronic pain?



Question 13

Were you referred to them by your GP?

YES
61.22%

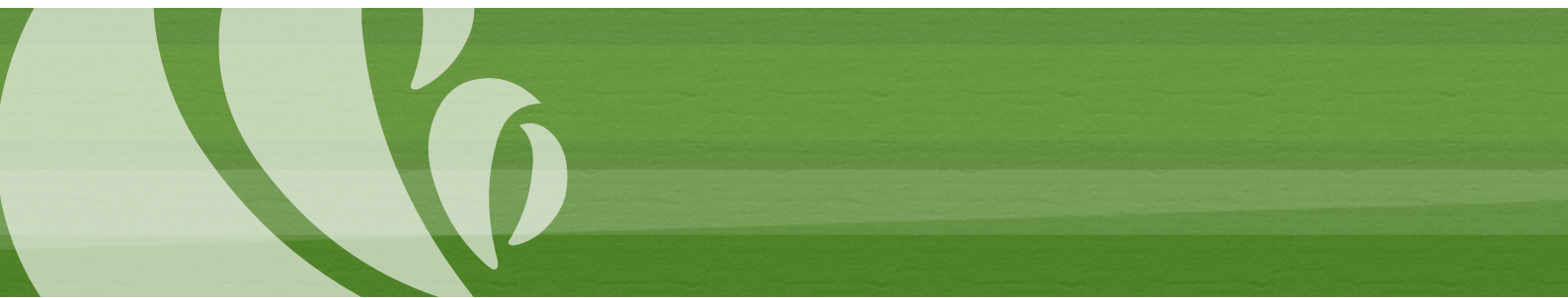
NO
38.78%

Question 14

Do you find accessing these health professionals easy?

YES
52.04%

NO
47.96%



Question 15

How do they help you manage your chronic pain?

They help me move.
They help me cope with daily pain.
They allow me to have a life outside of the pain.
They make my life easier.

- Relocating dislocated joints, healing chronic injuries and helping me gain strength to hold my body together
- They provide me with coping techniques both mental and physical.
- They offer me with practical solutions to obstacles like getting up the stairs on my own.
- I am managing two chronic conditions which are both incurable, they approach treating these from a holistic point of view, looking at the bodies' various systems and breaking it down to a functional level
- By offering a holistic approach to pain management
- They help me moderate my pain and help me gradually increase my resilience and strength
- They help me get my body moving again which reduces my pain
- My Pain Specialist has helped me immensely and I can now have a life again
- Seeing them is like a tune up for my entire body
- They provide a more natural approach to pain management
- They don't really provide me with any real benefit
- They help me understand what exercise I can do
- The massages I receive make me feel better and reduce my pain and give me better movement in my body
- I learn techniques to manage the mental side of pain
- They all work collaboratively together – I have a great team

Question 16

Do you find utilising these professionals affordable?

YES

16.27%

NO

83.73%



FEDERAL GOVERNMENT

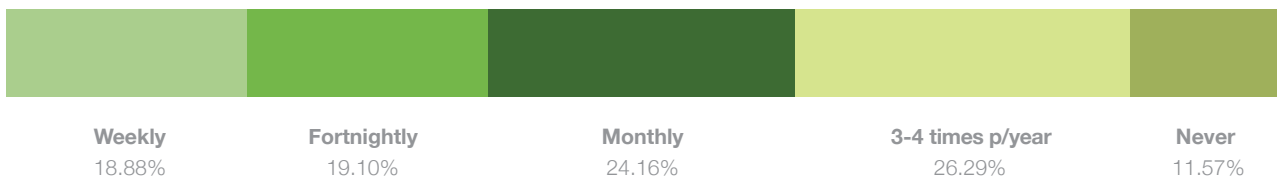
Question 17

Do you think the government should provide a full or partial rebate for accessing allied health professionals to manage chronic pain?



Question 18

How often do you visit other health professionals?

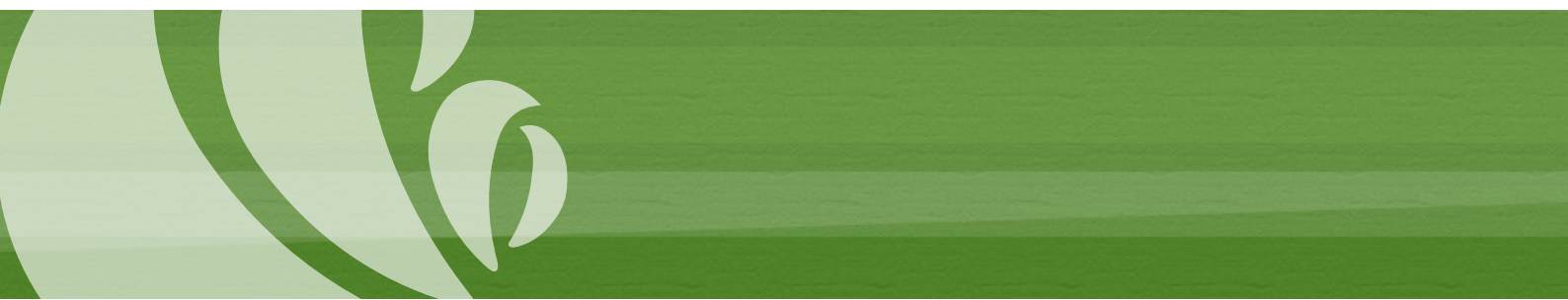


Question 19

What do you think the most important thing is that governments can do to support people living with chronic pain?

“Don’t put us all in the same box. Stop pulling the rug out from under us when taking drugs off shelves or making them harder to acquire. If we are being monitored by a pain management specialist, then we should not have to jump through bureaucracy hoops or have our GPs scared to prescribe stronger drugs. Government should be protecting us from the medical professionals who promise pain relief they can’t deliver. Such as surgeons implanting devices that are known to fail/not work at all. Or doctors performing other invasive procedures that don’t have a documented rate of success.”

- Provide more long-term health plans and more affordable ongoing treatments.
- Provide more public pain clinics and subsidise access to specialists
- Provide better Centrelink support to us
- Help with the cost of GPs, specialists and other health practitioner appointments



Question 19 (continued)

“Increase funding visits to allied health professional, the Chronic health care plan available form a GP with 5 visits per calendar year, is not enough - many people with ongoing pain require regular appointments with multiple allied health professionals”

- Understand that chronic pain can be a disability and not just a symptom and do more to educate the wider community about its impact
- Ensure we have access to the treatments we need at affordable process, so that we can remain functioning members of society
- Help remove the stigma of living with chronic pain
- Make medicinal cannabis more available and affordable

“Funding through the NDIS and DSP for those with chronic pain conditions. The current criteria is way too restrictive and the hoops we have to jump through are exhausting”

- Easier access to mental health professionals who I can afford
- Further invest in evidence based pain programs
- Do not restrict needed medication
- Opiates aren't necessarily the enemy and that when used as prescribed can make life bearable
- make the DSP and NDIS accessible
- provide more community based education resources we can use to manage our pain
- Acknowledge that our pain is real and affects our entire life

“Recognise that affordable allied health services mean I can stay in the workforce longer and contribute to society reducing the overall burden on the health system”



STIGMA

Question 20

How would you rate your feelings of stigma or negative attitudes because of your chronic pain?
(One being not at all and 10 being constant)

7/10
Average

Question 21

If you do face stigma, can you provide examples of situations when you felt stigmatised?

“

People don't understand when you say no to activities or have to leave early

I have been treated like a drug seeker by many GPs and specialist, even if I refuse pain relief to prove I just want help with pain management and daily injuries – but I was treated like a hypochondriac instead

The belief that because chronic pain can't often be seen, it permits judgement on the degree and debilitation of pain.

Being abused every time I park in disability parking with my permit on display. People tell me I shouldn't be parking there because I don't look disabled

Countless times being told that you do not look like you are in pain – therefore you are expected to do things that cause extra pain

Hospital admissions, where they don't give you your prescribed pain relief because they don't believe you need it or think you are a drug seeker

A lady told me I should wear long dresses so people don't have to see my brace that I need to be able to walk

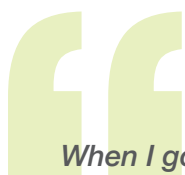
Being rejected by medical professionals because they say I'm too young to have chronic pain and I don't look sick

Taking time off work for my pain and my employer giving me a written warning for not going to work because of my pain which saw me go to hospital that day

Been told that I am a bludger, that I can do things when I so choose, and that I am wasting the taxpayers money. That I don't deserve a disability parking permit.

”

Question 21 (continued)



When I go to buy pain relief medication and questioned on why I need it.

My friends believing that my pain should all be over by now

Being told pain is a state of mind and if I got some hobbies and friends it would improve

Being made to feel like I don't do enough to manage my pain and that somehow I am responsible for the pain that I have

People just not understanding what it is like to live with chronic pain all the time – there is no off switch for my pain

People can't see my pain – therefore it doesn't exist

Friends who do not understand my condition and expect me to have normal behaviour and do the same things they can do

Being told/having implied that I am not trying hard enough

Was sent to a physician who stated that chronic pain did not cause disability

Inability to socialise, people react negatively to invitation refusals

My psychiatrist wrote to my GP telling them I was a hypochondriac

I told a friend that I had been diagnosed with Fibromyalgia and she told me that I needed to health my mind, body and soul and then I would be fine – ummmm no thanks

I don't face any stigma

*“That's a high dose for someone so young”
– doctors and pharmacists*

Holding people up in public due to my slow walking speed and they get mad at me

Nearly every time I am out using my walker someone will say “you are too young for a walker”. Many times this is followed by “Have you tried this or that treatment”, the inference being I haven't looked far enough for a treatment of haven't worked hard enough for it to be effective.



Question 22

What do you think the public should understand about living with chronic pain?

- That my pain is real – I'm not faking it
- The pain is exhausting and debilitating
- A wheel chair is not the only indicator or proof of pain/limitations/disability
- That pain is ongoing it doesn't just get better and it is a serious condition
- We aren't lairs
- You can't always see the pain
- I am not a drug seeker!

“It's debilitating. I'm not lazy, I just can't do it all and some days I can't do anything. I have no control over it and even when I do everything the best way possible I may still get pain. Being in constant pain is draining, physically and mentally”

- The pain is constant and wears you down
- Just because you can't see my pain – doesn't mean that I am not in pain
- The pain can take over your life and be very isolating

“Just understand. Have some compassion. Have some common sense, not everyone has a perfectly aligned spine, not everyone has a high pain threshold.. not everyone can cope without relief, not everyone can just suck it up and be tough. We need kindness from people, not vilification. We are victims of our pain and now we are victims of the system too and we feel like we are being left behind”

- For some types of pain there is no reason as to why it starts – it could happen to you too!
- Many people hide their pain and even though they look ok from the outside it doesn't mean they aren't struggling
- We are not hypochondriacs
- The pain affects our mental health too
- My pain changes day-to-day some days are good days, some days are bad days
- My pain isn't going away just with one physio appointment
- People of all ages can live with pain
- We get fatigued quickly
- You can't just pop a pill or sleep it off – the pain is always there.

“That we aren't complaining about a stubbed toe or simple tooth ache, we have pain that has been around for years and in some cases does not go away at all so when we say we are in too much pain today to do something don't compare it because you have no idea how draining it is to be living with constant pain 24/7 and sometimes we do need a break”

Question 23

How important do you think it is that the public understands what it is like to live with chronic pain?

8/10
Average



MEDICINAL CANNABIS

Question 28

What do you think about the use of medicinal cannabis in the management of chronic pain?

“

I think it can help a lot of people manage their pain

I don't know enough to comment

Amazing and the way of the future

I'd love to be able to try it. Availability is too restrictive and too expensive

I'd like to try it but the cost makes it out of reach

I don't think the evidence is strong enough to support the widespread use and financial support it

I'm all for it, would love to give it a go, anything for some relief

If I could access it I certainly would. If I could get off the mind numbing endless pills I need to get through a day I would in a heartbeat.

I think it has its place but only for certain people and conditions

I think it is a fantastic idea, and would much prefer it to using heavy opioids. However, as is always the case, the moral panic has made accessibility and affordability a key issue.

I think it is very helpful for many ailments and if it gets people off higher strength drugs then it's great. The government needs to make it much more accessible for trial. The price of the government sanctioned stuff is a bloody travesty, that's not helping anyone.

If it helps a person to keep living their day-to-day life without as much pain then I support it

Whole heartedly approve. I use CBD oil which helps

Good for some, but not interested in it for myself

Absolutely for it! Including medications that contain THC as well. It works like nothing else in my experience.

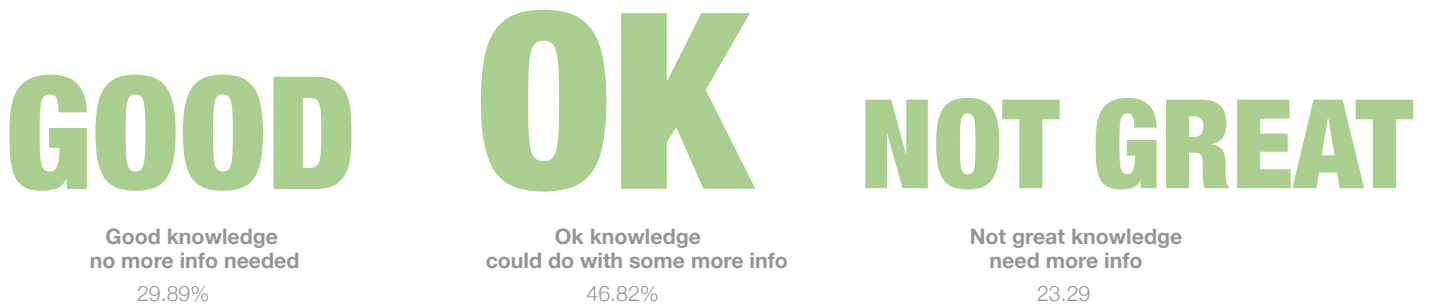
I think it's the way to go however it's very hard to find a GP who will prescribe it! Especially if you are living in a small country town.

”



Question 25

How would you rate your knowledge of the science behind medicinal cannabis?



Question 26

Have you spoken to your GP about accessing medicinal cannabis?



Question 27

What was their response?

“I asked my pain specialist and he just scoffed at me – said that everyone just wants to get high for free”

- They had no idea about it
- Didn't ask as my GP is not open minded
- Very negative – said there is not enough evidence

“It is easier to buy it illegally than it is to have it legally approved. Just get some and don't tell anyone”

- Supports it – my pain specialist has already made the prescription
- Too much trouble to deal with
- Was told it is not available
- Was told my GP couldn't prescribe it
- I was advised not to take it
- Laughed at me
- Very dismissive
- Open to the option

“They rolled their eyes at me. They looked at me as a junkie. They judged me and deemed my need for an opiate as a sign of my drug dependence. It was disgusting. I was disgusted. They were horrible. I went home in pain.”

“He said no, it was illegal, but then suggested I smoke a few cones! My pain specialist however referred me and I am approved for use”

“He was laughing his head off. My neurologist was willing to prescribe it, but added that I probably would not be able to afford it.”

“Very supportive – I gave him lots of information and he looked through it all”

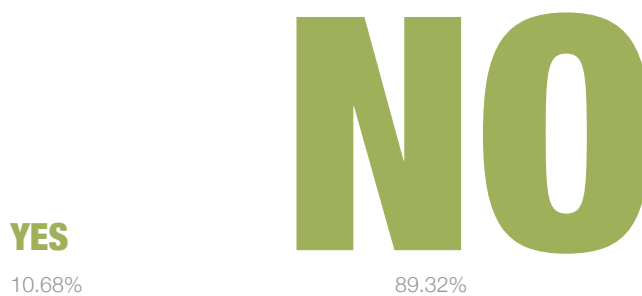
“He suggested it to me – so did my specialist”

“Did not want me to take it and compare it with when doctors prescribed cigarettes stating no clinical studies on side effects”

- I didn't ask because I was scared
- I know I can't afford it so didn't ask
- My GP told me it was illegal to use cannabis
- On the fence about it

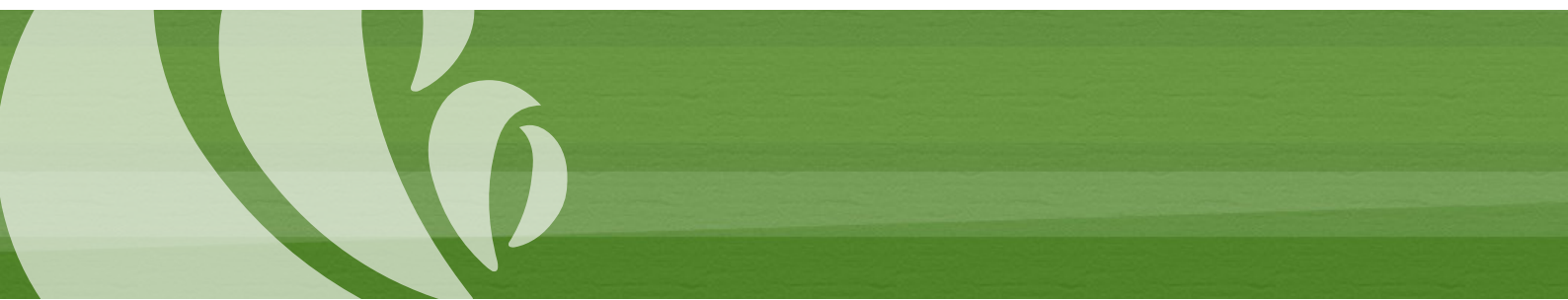
Question 28

If you have been discussing medicinal cannabis with your GP for more than 12 months, have you noticed a change in their willingness to prescribe medicinal cannabis?



Question 29

Did you know that a pain specialist can provide a prescription for medicinal cannabis?



COVID-19

Question 30

During COVID-19 has the way you manage your pain changed?



Question 31

If yes, how?

- No access to gym/bike/spa/hydrotherapy pool making exercise very difficult
- Less support – harder to access medication and see medical professionals

“I am immunocompromised so I can’t go to the clinic and need to do everything virtually or over the phone to stay safe”

“Strangely it has had a positive effect – life has been a lot less stressful in my family situation”

“Working from home has helped give me more energy”

- I use telehealth a lot for my GP and pain Specialist appointments
- Couldn’t see my usual doctor during pain flares
- Have been using more drugs because I can’t access other therapies at the moment
- I just put up with the pain

“I feel my pain is exacerbated by the stress of COVID-19”

- There hasn’t been a change to how I manage my pain
- I’m experiencing more pain, medicating more and not using any allied health services
- My surgery was cancelled
- I have not been able to get my Ketamine Infusion

Question 32

Have you utilised technology/telehealth to meet with health practitioner during COVID-19?



Question 33

Did you feel a benefit from using telehealth?

YES

66.91%

NO

33.09%

Question 34

If yes, why?

- It's a great option when I am too unwell to attend an appointment in person

"I felt safe and was less stressed trying to find time to get into the doctor when trying to work full time"

- Saves me so much time than going to in person appointments

"I am confined to bed mostly. It is so important to have access to my doctor without having to travel to see him. Telehealth is a very important advance for the disabled."

- It's very easy to access the health professionals I need to

"Telehealth is awesome. I have to get scripts from my doctor regularly and end up sitting in a waiting room for hours in pain for no reason. Most of my medications are long term and do not require a review every single time I need a new one. I hope they continue to offer these after lockdown."

- Telehealth helped maintain momentum of my treatment and I have been able to access help during COVID-19

"Fewer access barriers for people like me with a physical disability"

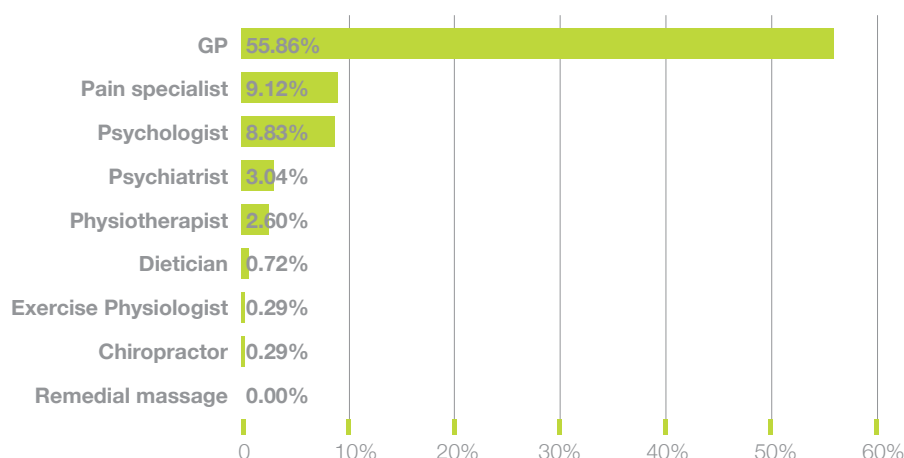
- It keeps us all safe

"A lot of problem solving can be done over the phone/video chat. It saves a lot of energy and time not having to physically attend the doctors."



Question 35

What practitioners are you seeing using telehealth?



Question 36

If you faced barriers accessing telehealth, please describe what they were?

- My condition needs physical examination
- Hard to know who is available through telehealth and how to access it
- Ability to have privacy during a consultation in a shared home
- I worry about my privacy and confidentiality using telehealth
- It's only available to me over the phone not via video which I would prefer
- The internet is not good enough in my area
- My health professional refuses to see me via telehealth

“I am not comfortable discussing my mental health issues online”

“My doctor phoned me even though I suggested video conferencing. He could not examine my movement at all. Pointless.”

“I prefer face to face even if I have to travel. Least at the Pain Clinic particularly with the physio they can ensure any exercises you do are being done correctly. You cannot see which muscle groups are being tensioned over telehealth”

“Some health professionals you just need to see face to face. Like physiotherapists, so telehealth is a bit pointless. Tried to arrange a telehealth appointment with an orthopaedic surgeon last month but they said no. Ended up seeing him face to face.”

Question 37

Do you have good internet connection in your area?

YES

88.17%

NO

11.83%

Question 38

Do you feel that you have all the technology you require to engage with your health practitioners through telehealth?

YES

81.63%

NO

18.37%

Question 39

Would you consider using telehealth options with your health practitioner once COVID-19 is over?

YES

59.44%

NO

19.85%

UNSURE

20.71%

Question 40

Over the last 12 months have you experienced a disruption to accessing your medication?

YES

41.17%

NO

58.83%

Question 41

If yes, can you tell us what happened?

“My chemist doesn’t always have one of my medications in supply despite knowing it is a regular requirement”

“Hospital based ketamine infusions were cancelled – they have re-opened recently, however I am not willing to be in hospital right now because of COVID-19”



Question 41 (continued)

“I take hydroxychloroquine and since Trump declared it would cure COVID-19, it has been hard to access”

“A previous GP called me an addict and cut my supply off despite taking low dose opiate and having approval from my pain specialist”

“A doctor wouldn’t prescribe me pain meds – he actually prayed for me instead”

“My doctor was unavailable and I saw another doctor who didn’t believe I was in pain or should be on that tablet therefore he was not willing to give a repeat of the tablet despite needing it until my surgery is back because of COVID-19”

- Harder to purchase pain relief from the pharmacist due to new restrictions
- The pharmacy was out of my medication
- My regular GP was away and the replacement GP refused me medication
- My pharmacist was out of my medication due to increase demand from people because of COVID-19



NATIONAL PAIN SURVEY 2018 – 2020

Key themes and metrics analysis

Overview

Each year for National Pain Week, Chronic Pain Australia, the grass-roots voice of Australians living with chronic pain, produces the National Pain Survey to hear directly from people living with pain about what they need to improve their lives.

Since 2018 the survey has taken a similar design which was a deliberate decision by Chronic Pain Australia so it could track the opinions and sentiments of people living with pain on key issues including the relationship between people in pain and their GP, pharmacist and allied health professional.

The relationship between people in pain and their health practitioners is incredibly important to the way pain is managed by an individual and their quality of life. Chronic Pain Australia knows through years of National Pain Surveys and individual story-telling and self-advocacy that chronic pain is best managed when the person in pain has a great working relationship with their GP, pharmacist, allied health professionals and is able to lead their own healthcare.

This person-centered approach which empowers the person in pain to lead the decisions being made about their health is one which Chronic Pain Australia deems as best practice and is only made possible when the working relationship between a person in pain and their chosen healthcare professionals is positive, professional and solutions focused.

What is often stopping people in pain from achieving this best practice relationship is stigma. Each year through the National Pain Survey people in pain have consistently reported feeling stigmatised, not believed and experiences of being labelled a drug seeker when they visit their healthcare practitioners. What has been made very clear by people in pain through the survey period is that this stigma has made people in pain less trusting of healthcare professionals and less hopeful anything can be done to improve their situation which in turn often makes the stigmatised person less able and willing to be a leader in their pain management. The reverse is true in situations where people in pain have positive working relationships with their healthcare professionals.

Stigma is also felt by people in pain from their family and friends and by the public. During the survey period, people in pain have consistently reported not being believed by their friends, family and co-workers about the level of pain they are experiencing, particularly if the person in pain does not fit the stereotypical view of what it is to be someone living with pain, which many view as being an older person's illness consisting of general aches and pains. Not being believed by the people closest to you has a significant negative impact on a person in pain's physical and mental health.

Another very common form of stigma reported by people in pain is using disability parking spaces. Many people in pain have qualified for disability parking and display the disability pass in their car. Usually when people in pain are driving it is only because they are having a good pain day and their pain is manageable meaning they can do every day activities like go to the supermarket or shops but still need to utilise the disability parks. It is important to recognise that just because someone is having a good pain day does not mean that their pain is complete gone. Chronic pain by its very name is continuous, it is the level of pain being experienced by someone which varies. Because people in pain live with an invisible illness, they often appear to look fine to members of the public and because of this many people in pain have reported being yelled at, followed and verbally abused by members of the public when they use a disability parking space. For many this is a frightening experience and is leading to more and more people in pain feeling like it is easier to put up with their pain by using a car park further away than using the disability car space which they are perfectly entitled to. Chronic Pain Australia believes this type of stigma and discrimination against people in pain has no place in modern Australia and must stop.



Finally, the National Pain Survey has overwhelmingly demonstrated the support in the chronic pain community for the use of medicinal cannabis in the management of chronic pain. During the survey period it has shown an increase in support of medicinal cannabis by the chronic pain community, however the regulatory barriers, GP knowledge and willingness to prescribe medicinal cannabis and the cost are all barriers for people accessing it. During the last three years, Chronic Pain Australia has seen more of its members reporting being prescribed medicinal cannabis and for the majority the medication has seen a dramatic improvement in not only their pain levels but also their quality of life.

This report will discuss what the 2018-2020 National Pain Surveys have demonstrated about people in pain's sentiments regarding five key themes which were all featured in each year of the survey period. The five key themes are, the relationship between people living with chronic pain and their GP/pharmacist, the role of allied health in pain management, stigma, the role of governments and medicinal cannabis in the treatment of chronic pain.

The relationship between people living with chronic pain and their GP/pharmacist

The surveys have consistently found that GPs and pharmacists make up a critical component of a person in pain's medical treatment team with more than 50% of people each year reporting that they visit their GP and pharmacist every 2-4 weeks.

What is also very clear from the surveys is a downward trend year-on-year in the relationship between people living with chronic pain and their GP and pharmacist. In 2018 when asked 'On a scale of 1-10, how well do you think your GP manages your chronic pain?' GPs received a score of 9/10, then 8/10 in 2019 and just 5/10 in 2020. For pharmacists, this question was asked in the 2019 and 2020 surveys with pharmacists receiving a score of 8/10 in 2019 and worryingly 4/10 in 2020.

However, while the relationship scores may have declined, the main messages of what people in pain think a GP and pharmacist should know, understand and do when treating someone with chronic pain has remained almost identical across the survey period. The main things people in pain reported against this were:

- My pain is not made up – believe me when I say I am in pain
- I am not a drug seeker
- Actually listen to me and hear me and what my needs are
- The pain is debilitating, and it doesn't stop which takes a toll on my whole body
- Understand how my mental health suffers because of my pain
- Further education is needed by GP/pharmacists on the different types of pain
- Learn about medicinal cannabis and how it can be used to manage chronic pain
- Treat me with compassion and understanding

When asked about the one thing a GP or pharmacist could do now to improve a person in pain's situation there were common responses across the survey period, including:

- Be my advocate
- Help prescribe medicinal cannabis
- Refer me to other appropriate services
- Tell me what my non-medication options are
- Hear my whole story and help me manage my pain
- Be more helpful and understanding
- Don't be skeptical of me or judge me



The role of allied health in pain management

The survey period demonstrated very clearly that allied health has a central role in pain management. Of the most commonly utilised allied health professionals are physiotherapists, pain specialists and psychologists, however most people who use allied health as a treatment option report seeing a combination of allied health professionals.

Across the survey period more than 60% of people reported being referred to an allied health professional by their GP. There has been a slight decrease over the years of people accessing allied health through their GPs referral peaking in 2018 at 67% now down to 61% in 2020, however this figure still demonstrates the need for GPs and allied health professionals to interact and know of each other's services.

When asked how allied health professionals help people manage their pain common responses across the survey period included:

- They help get my body moving
- They help in educating me about my pain
- They provide me with natural therapies
- They provide me with techniques to deal with the mental aspects of pain
- They help me try new management techniques

What has been made very clear throughout the survey period is that it is not affordable to use allied health professionals with more than 80% of people surveyed saying that they do not find these services affordable across the survey period. People in pain have consistently agreed (95%) that the federal government should provide a full or partial rebate for accessing allied health services in the management of chronic pain during the survey period.

In good news there is evidence that indicates people in pain are finding it easier to access allied health professionals. In 2018 when asked "Do you find accessing these (allied health) professionals easy?" 42% said yes, but in the 2019 and 2020 surveys this response rose to 51% and 52% respectively.

Stigma

As mentioned earlier in this report, stigma remains one of the biggest issues for people living with chronic pain. In 2018 the survey asked, "Do you feel that you face stigma or negative attitudes because of your chronic pain?" which 86% of people answered yes. In 2019 and 2020 the survey asked a slightly different question asking people to rate out of 10 their feelings of stigma or negative attitudes due to their chronic pain. In both years, the average was 7/10.

People in pain have said across the survey period that they wished people who don't live with pain would believe them when they say they are in pain, they aren't just talking about a slightly sore back or stubbed toe, how the pain makes everyday life difficult and that what they need to get through their pain is some support and kindness, not skepticism and hostility.

Chronic Pain Australia is committed to stigma reduction for people living with chronic pain, we know that reducing stigma engages more people in their healthcare, makes life easier for people living with chronic pain and ultimately saves lives.



Below are some direct quotes from survey respondents during the last 3 years which describe how people have felt and have been stigmatised against just because they live with chronic pain.

“I feel stigmatised anytime I say I can’t do something and I get ‘you’re a fit young 20 year old’ back as a response. People don’t recognize the seriousness and extent of my daily pain. They assume I’m making it up or being a sissy. They tell me to harden up and get through whatever activity I’m doing that I feel I can do, simply because they can’t see my illness, until they push me too far and I literally cant walk or bend, then they take notice. I’m so sick of not having enough money to live a basic life because I’m too disabled to work, but doctors won’t listen to me, and Centrelink won’t let me get disability unless a doctor says I need it and everyone just looks at me like a lazy dole bludger, and it makes me feel so worthless. I want to do things and I do when I can, I just can’t work a full-time job, but don’t have the obviousness of a physical disability like being handicapped so no one takes me seriously when I try to engage in the welfare system we have set up for that exact scenario. I’m stuck in a weird place where I only get youth allowance and can barely afford to live, let alone save and get to do things in life because I can’t work but don’t have anyone that takes me seriously enough that I can get disability. I’m discriminated against and stigmatised by everyone from doctors, to Centrelink workers, to my job service providers, to the government itself, who will on one hand give my nan disability for having arthritis in her knee, but because I’m a young male, they just look down on me as a bludger and decide I’m not worthy of help from the system that is there to help me, despite the fact that I have worse pain in more areas than my nan.”
[2018 survey respondent]

“I feel stigmatised when my normal doctor is away and I need a script. You get interrogated firstly and then made to feel guilty for being in pain because the other treatments haven’t worked and he/she tells you that you haven’t obviously given them a chance and taken the easy way out. Even though you’ve tried everything over and over again for 4 years and the only thing that can help make your life even half worth living is the medication that you’re now being shamed for using because it was the last resort. He didn’t look at my chart notes that explained everything. The only notes he went straight to was my prescription history and saw the medication that I’m on and labelled me even before I sat down. Being belittled, degraded, shamed and then trying me best to hold back the tears, nod my head in agreement because I must be what he says I am so I can get the medication I need.”
[2019 survey respondent]

“My GP makes me feel like I’m drug seeking when I tell him about my pain. I had a really bad hip, I told him it was 10/10 on the pain scale, he looked at me and said ‘Really....I don’t think it is, it’s just normal wear’ he went away on holiday so I went to his partner who agreed to give me a referral to a surgeon. The surgeon looked at my radiology, looked at my leg and picked the phone up and rang theatre to see if he could extend his theatre session. I was rushed through and he said it was one of the worst hips he’d ever seen and couldn’t believe I’d functioned with it. And my GP didn’t believe I was in pain!!!”
[2019 survey respondent]



“Nearly every time I am out using my walker someone will say ‘you are too young for a walker’. Many times, this is followed by ‘Have you tried this or that treatment?’, the inference being I haven’t looked far enough for a treatment of haven’t worked hard enough for it to be effective.”

[2020 survey respondent]

“A lady told me I should wear long dresses so people don’t have to see my brace that I need to be able to walk.”

[2020 survey respondent]

“Being made to feel like I don’t do enough to manage my pain and that somehow I am responsible for the pain that I have.”

[2020 survey respondent]

“Being abused every time I park in disability parking with my permit on display. People tell me I shouldn’t be parking there because I don’t look disabled”

[2020 survey respondent]

The role of governments

The survey period demonstrates that people in pain believe that governments do have a role in supporting people living in pain. The survey results suggest key areas and ways in which governments can provide that assistance which include chronic pain being added as a qualifier for the Disability Support Pension, an easier process dealing with Centrelink, providing better support and access to medicinal cannabis including making it more affordable.

The survey period also demonstrated that people in pain want politicians to understand what it is like for them to live with chronic pain and to help provide more funding to make treatment options more affordable.

At the start of the survey period the Commonwealth Government introduced its restriction on selling codeine-based products, which is a common form of pain relief medication. In the 2018 survey 70% of people said that they disagreed with the government’s decision to up-schedule codeine with many reporting that they felt this change was unfair on people who had managed their medication well for many years under the guidance of their GP, pharmacist and pain specialist and indeed they were only taking this medication because their GP had prescribed it for them.

The results of codeine up-scheduling continue to be felt by the pain community. Since the up-scheduling Chronic Pain Australia has heard of numerous cases where people have either had to fight tooth and nail with their GP to get their regular medication and in some instances when their GP did review their medication a higher dosage was prescribed after review, which seems to defeat the purpose of the up-scheduling. Another very common response from people in pain has been that they now suffer in silence because their GP will not prescribe them the medication they need to manage their pain.



The below quote from a 2020 survey respondent articulates well very common responses Chronic Pain Australia has received during the survey period when it asks ‘What do you think the most important thing is that governments can do to support people living with chronic pain?’

“Don’t put us all in the same box. Stop pulling the rug out from under us when taking drugs off shelves or making them harder to acquire. If we are being monitored by a pain management specialist, then we should not have to jump through bureaucracy hoops or have our GPs scared to prescribe stronger drugs. Government should be protecting us from the medical professionals who promise pain relief they can’t deliver. Such as surgeons implanting devices that are known to fail/not work at all. Or doctors performing other invasive procedures that don’t have a documented rate of success.”

Medicinal cannabis in the treatment of chronic pain

The want of the chronic pain community to access medicinal cannabis in the treatment of their pain has been one of the biggest findings during the survey period. In 2018 there were no questions relating to medicinal cannabis asked, however medicinal cannabis was continuously raised by survey respondents as an answer, particularly in questions which asked what your GP/pharmacist/the government should be doing to help you manage your pain?

The 2019 survey did have a set of questions relating to medicinal cannabis which revealed that people in pain were keen to at least try it to manage their pain and increase their quality of life but that a lack of knowledge, GP willingness to explore it as a treatment option and burdensome paperwork and cost were all access barriers.

In 2019 almost 78% of survey participants reported that they had a good or ok working knowledge of medicinal cannabis in the treatment of chronic pain. Later that year Chronic Pain Australia ran a series of national consumer education workshops which outlined the research and evidence of medicinal cannabis and also saw GPs, pharmacists and consumers share their experiences with medicinal cannabis for the treatment of pain either personally or through their experience treating someone living with pain. What these workshops demonstrated was the amount of research people in pain had done regarding medicinal cannabis and chronic pain management. In the 2020 survey the amount of people reporting that they had a good or ok working knowledge of medicinal cannabis remained steady at 76%.

In both the 2019 and 2020 surveys just over a 1/3 of people said that they had spoken to their GP about potentially using medicinal cannabis as part of their treatment but had a very negative and worrying response from their GP as the below responses indicate.

“Dismissed and rejected by multiple doctors and pain specialists, who unfortunately are not only ignorant of the growing evidence base for medicinal cannabis but are not even open minded enough to consider the evidence.”

[2019 survey respondent]

“They rolled their eyes at me. They looked at me as a junkie. They judged me and deemed my need for an opiate as a sign of my drug dependence. It was disgusting. I was disgusted. They were horrible. I went home in pain.”

[2020 survey respondent]

“He said no, it was illegal, but then suggested I smoke a few cones! My pain specialist however referred me and I am approved for use.”

[2020 survey respondent]



*“He was laughing his head off. My neurologist was willing to prescribe it but added that I probably would not be able to afford it.”
[2020 survey respondent].*

*“Did not want me to take it and compare it with when doctors prescribed cigarettes stating no clinical studies on side effects.”
[2020 survey respondent]*

*“I asked my pain specialist and he just scoffed at me – said that everyone just wants to get high for free.”
[2020 survey respondent]*

Chronic Pain Australia recognises that access to effective pain management is a human right, and that barriers to access should be removed where it is practical and safe to do so. Access to Medicinal Cannabis where it is a legal treatment option should be subject to the same regulatory and evidentiary standards as all other medications used in the treatment of pain.

Further, Chronic Pain Australia believes that barriers to access such as regulatory burden, stigma, lack of investment in research, and low uptake of opportunities for professional education by health professionals need to be overcome in order to allow medicinal cannabis to take its appropriate place as an option in a multifactorial care plan for a person in pain. Chronic Pain Australia’s full position statement on medicinal cannabis for the treatment of chronic pain is attached to the end of this document.

The 2020 survey indicates that slowly GPs are becoming more open to the idea of medicinal cannabis with their chronic pain patients as 10% of surveyed participants said that during the last 12 months their GP had become more willing to discuss it with them.

