

# Severe asthma - uncovering the reality



## A qualitative study of the lived experience of Australians with severe asthma

**EXECUTIVE SUMMARY AND FINAL REPORT**

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**WOOLCOCK**   
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Australia

# This report

This report is the result of a project jointly conducted by Dr Juliet Foster, Associate Professor Helen Reddel and Dr Michael Guo of the Woolcock Institute of Medical Research and Associate Professor Vanessa McDonald of the Hunter Medical Research Institute, in partnership with Asthma Australia.

Australia has one of the highest rates of asthma in the world. Current asthma treatments are mostly very effective, but 5-10% of people have severe refractory asthma, i.e. asthma that does not respond adequately even to high dose treatment. People with severe asthma face a sizeable burden in their day-to-day lives, over and above that of people with milder disease. Yet little is known about the life experiences of these patients, since very few qualitative studies have specifically researched people with severe asthma.

The focus of this study was to explore the experience of Australians living with severe refractory asthma, and their perceptions regarding the impact of asthma and asthma treatment on their quality of life and capacity to have the kind of life they want; what management of severe asthma involves, and their experience of medication use including side-effects.

We also asked people about their experiences of asthma flare-ups (exacerbations), and how they cope with these. An important aspect of the project was to explore Australians' experiences of asthma care in primary and secondary care settings and to identify their unmet health care needs, as well as effective materials or resources to support their future care.

Twenty-five people with severe refractory asthma were invited for interview via the Australasian Severe Asthma Network and/or secondary care asthma clinics in New South Wales/ACT, South Australia, Victoria, Tasmania, Queensland and Western Australia. The interviews were conducted by telephone, and ethics approval was obtained from the University of Sydney Human Research Ethics Committee. Participants ranged in age from 23 to 81 years, 68% were female, 48% lived in a disadvantaged socioeconomic area<sup>1</sup>, and 16% lived in a regional location, outside of a major city.

<sup>1</sup> Socio Economic Indexes for Areas (SEIFA), Index of Relative Socio-Economic Disadvantage (IRSD) 1 – 3 (1 is most disadvantaged, 5 is least disadvantaged). [www.abs.gov.au/](http://www.abs.gov.au/)

# Daily symptom burden

Almost all people interviewed experienced daily shortness of breath, wheeze, cough or other symptoms and most experienced frequent night-waking due to asthma. Some people with severe asthma were extremely debilitated, for example, on a typical day they were unable to speak in full sentences or walk to the end of their street.



Figure 1: Word cloud of daily asthma symptoms described by participants with severe asthma

“I don’t feel like I’m getting a lot of breath in. I’m very restricted and tight in the chest and [breathing] doesn’t even feel like it’s doing any good. Depending on the day, [I could be feeling like this] all day, three quarters or maybe half the day. I don’t think I’ve actually had a full day, feeling capable of just doing things, like showers for a year and-a-half.” Casey\*, 48 years, NSW/ACT



\*All names in this report are pseudonyms, and stock images have been used.

# Impact of asthma on daily life

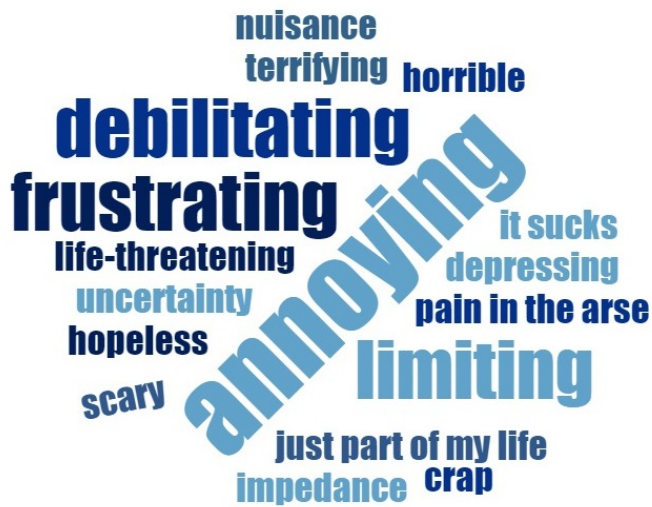


Figure 2: Word cloud showing the single words or phrases participants chose to describe what having severe asthma is like for them

Few people used positive words or phrases to describe what living with severe asthma was like for them. Most chose words reflecting the limitations and frustrations felt in response to those limitations, while others focused on the fear that accompanies asthma attacks.

Severe asthma hinders the lives of patients in many ways including relationships, sex, pregnancy, parenting, family interaction, friendships, socialising, work, career choice, travel and physical activity, from sport to simple daily tasks.



“I have lost in every facet of my life. You know, my earning capacity, my, my self-esteem, my um, eh, sense of achievement, my relationships. You name it it’s been there. And my asthma has been this severe all of my life.” Rhonda, 54 years, NSW/ACT

“When my kids were [small] I would be sick and I'd try and pick them up and I just didn't have the energy, and I felt terrible. I thought ‘((gasp)) I'm a Mum I should be able to just pick them up and put them over my shoulder and off I go.’ But I couldn't. There was many times I couldn't do that, so I would lay on the floor with them and play with them that way.”

Brenda, 53 years, VIC

Many people with severe asthma feel compelled to continue to work or take care of their family when they are sick, “pushing through” due to factors such as work or financial pressure or not wanting to let others down. In many cases this led to delays in seeking acute care for asthma.

“So you’d be doing that all day long, and each time getting up the stairs knowing what I’m in for, for another you know, um severe, severe sort of recovery. Um, it was pretty stressful and by the end of the day you, you’ve got the most incredible headache eh, and um exhausted and everything else. Where it should, should’ve been a fairly straightforward easy job. Eh, stuff like that, you know. So it was very distressing because you’ve got to keep up with the rest of the team.”

Larry, 54 years, NSW/ACT

“I suppose if I thought I was bad enough and they might put me in hospital, I’d probably hesitate going because I didn’t want to have to go to the hospital. So much to organise.

Like, getting your kids organised, and babysitters, and things like that.” Joan, 52 years, TAS

“And I’ve got a bad habit of doing that. I do tend to try and push myself. I did that quite a lot when my children were younger because I had to keep on going. You know, you just feel like you’ve got to do it. And all I ever wanted to do was be a mum, so that was my biggest pride and it is still. So um, I just felt like I’ve, I have to give it all.” Brenda, 53 years, VIC

## Mental and emotional health

Low mood or depression was common, and sometimes severe, among patients with severe asthma. Many patients described disappointment/frustration and feelings of hopelessness/worthlessness in response to the limitations imposed on their lives by day-to-day asthma. These feelings were often increased during periods of worsening asthma symptoms, recovery after hospitalisations or after retiring from work due to severe asthma.

“It’s frustrating, um upsetting, because I really want to. You know, there’s things I really wanted to do and I just haven’t been able to do it. Um, and that doesn’t help with the depression. It does make you depressed, because people look at me and they don’t see the sickness that has happened over my life.” Brenda 53 years, VIC

“On some occasions the mind’s there and wants to do it but the body can’t keep up. Um, and it sort of makes you feel worthless in a way.” Neil, 60 years, SA

“Uh mentally, uh it's, it's, you know, ‘Why is it happening?’. It’s an annoyance. I’m annoyed with myself that [shortness of breath has] happened. You know, I’m just thinking ‘Oh why the hell is it happening again?!’ Uh and I’m sort of cursing myself internally.” Keith, 64 years, VIC



Patients tend to conceal their struggle to cope with the impact of severe disease. It is notable that some patients fare better emotionally, particularly where there is good and willing support from a close family member or partner.



“My, my wife has always been a very encouraging source for me. She has been, um, tremendous in recognising my condition and assisting with my condition... She always uses ‘we’, she’s very much a plural person. ‘We can work through this.’ I’m not alone there. That encouragement. So, and for me that’s been a psychological strength.” Keith, 64 years, VIC

Psycho-social and mental health issues are often poorly addressed in the care of severe asthma patients. This leaves family members, if they are available, to not only run the household and manage parenting and financial/work demands but also to deal with their loved one's emotional burden.

In some cases severe asthma reduced the person's daily life to the extent that there was little pleasure left in life. Casey, who lived alone with little support, described believing she would probably die from asthma if her doctors couldn't help get her worsening exacerbations under control. She explained that the financial burden of asthma and the extent of loss to her quality of life sometimes made her wish to grab some life back even if it meant not being able to breathe or live anymore.

"The way this problem is not being fixed and the exasperations [sic] are getting worse, I don't think I probably need to worry about [taking] the osteo [treatment]. I think [dying's] very much a reality. I think maybe it comes down to, I can spend all of this money trying to get this treatment and seeing all these guys, and now it's been diagnosed and they just keep finding something else. And it's just like, well, just let it be done. Yeah once it's taken over every minute of my life, maybe I could just, I can get a little of it back and if I can't breathe in the process, so be it. ((voice cracks with emotion))."

Casey, 48 years, NSW/ACT



Interviewees explained that they felt physicians needed to more often initiate conversations to flag that emotional and quality of life issues are within the remit and/or of concern to the physician.

"I think [doctors] should ask how are you feeling yourself and things like that. But they don't and I can't force them so, I'm just lucky I've got someone to talk to otherwise I'll probably go bonkers...My husband, he's my friend and he's my husband see. But sometimes every now and then you need somebody else outside the family to talk to." Katherine, 59 years, WA

Interviewees also talked about the lack of emotional support from health care professionals, sometimes over a lifetime of asthma consultations, and a lack of expectation on their part that such help would be offered. People with severe asthma saw a benefit in such support both from their perspective and from the perspective of the health care professional.

“Well, I think it's, there has to be an acknowledgement that when you have um, any disease and you're on the, the pointier end of it in severity, that for the vast majority of people, depression is going to walk hand-in-hand with that. And so it [should] be treated along with the disease.” Rhonda, 54 years, NSW/ACT

“I guess it's a funny situation. It's something that's never happened. So like, I guess the doctors have never ever enquired about [how I cope with asthma in my daily life]. So I guess after 20 years of, 20 to 25 years of asthma, you sort of grow into it that way, it's like that's the way it's always been. It was only ever medically kind of addressed. Maybe if things were different back in the beginning I may have a different viewpoint now. Um, but the way it always was basically just medical, eh so that's the way I've always accepted it as being. Um, yeah I guess, you know, if things were different it, it could be good if doctors were more, more eh inquisitive about the broader aspects of the, of how the disease affects people.” Larry, 54 years, NSW

Interviewees suggested that ‘chronic disease life planning counselling’ would be beneficial in helping them juggle work and family life while dealing with asthma. It would allow them to plan their lives better, help them identify when external support is needed, and allow them to prioritise their asthma, particularly in times of worsening symptoms.

“Talking with someone about how to work your way around things and, just how to do things or even just a little bit of advice, you know. Like, ‘Look, if you can't do that don't stress about that, that's not [essential]’ you know. Putting your mind at ease that it's ok to have asthma and, and feeling a bit down. You're going to pick up but at the moment you just need, not, not like a counsellor, but some sort of therapeutic talk.” Brenda, 53 years, VIC



Those who were very debilitated by their severe asthma described a lack of discussion with their specialist about the extent of their disability and possible options such as accessing disability support.

“Well it could be an enquiry that doctors actually make or advise their patients if they can see that they are legitimately handicapped and suffering. They could maybe, you know, help them get that sort of thing organised or at least advise them of the availability of, of [support services for disability].” Larry, 54 years, NSW/ACT

People who had to retire through ill-health described the huge emotional impact of the loss of work and career in their life and the lack of structured support as they made the difficult transition to a new career or giving up work altogether.

“I loved my job and it was unfortunate that I had to give it up. And that was sort of a bit of a depressive time when you have to do that, “Cause, well I felt like I wasn’t functioning in society the way I wanted to... Alone at home, very hard on myself. You know very, very hard on myself. And I think that that had a lot to do with my depression.” Brenda, 53 years, VIC

## Self-management support

Patients described both practical and emotional support needs which they received from, sometimes reluctant, family members or did not receive at all. Examples included help getting to and from medical appointments or talking through disease-related limitations, life plans, or feelings with an empathic listener. Support needs often increased after hospitalisations, where inability to work or manage household tasks and feelings of disappointment in reaction to the set-back exacerbated depression and feelings of isolation.

Those living alone or without practical or emotional support often struggled most with self-management. These individuals often had a hectic lifestyle, felt isolated and/or ignored their symptoms. They were often at most need for emotional and/or practical asthma support outside their family unit, although they were often unable or unaware of how to access such support.



“When I started living on my own when my children moved out, that was very fearful for me. That was very, very ‘Oh my god! Will I be alright?’ And you know, one day I wasn’t alright. I had developed pulmonary emboli and I was really sick. But I didn’t realise it because I was still pushing through. It took my friend to drive [from 200km away] to tell me ‘You need to go to hospital.’” Rhonda, 54 years, NSW/ACT

“That’s how I portrayed things. I’d go, [my GP would ask], ‘Do you wake up at night?’, ‘Oh nah, sometimes’, because as I said, like, the whole thing is like ‘Oh Cheryl get on with it, look after your 4 kids, go to work’ you know, ‘make the dinner, do the ironing, blah, blah, blah. So get on with it’ ((laughs)).” Cheryl, 53 years, WA



Some people cope well with asthma symptoms and hindrances, adjusting their activities to what they *can* do, particularly those with support at home, and some older people found that, with age, the difference between their health and that of their non-asthmatic peers became less apparent.



“You readjust your life to how your life is. You know, I used to cycle 25km but I’d stop twice because I’d get out of breath. So I’d have some Ventolin and keep going. I wouldn’t not do anything because of my asthma. But it has, you know, numerous limitations.” Cheryl, 53 years, WA

## Carer support

Support from family or friends was considered vital, but it was also a concern to people with severe asthma, who realised the substantial burden it placed on those who support them.

“I’ve got my daughter coming over ‘cause I’m finding it hard like to do the housework. There are certain chemicals I can’t use. My husband has got to like, do most of the work, the bathrooms, the toiletry stuff. And my daughter comes home and she bakes, she mops, dusts and cleans for me.” Katherine, 59 years, WA

They talked about the need for more information for the people around them who are concerned either too much or little, with some loved ones under-estimating the impact of asthma on their functionality.

“If [friends or family] can go to a half way person or [the patient’s] doctor who says ‘If you are worried what are you worried about?’... Because [friends and family] worry about a lot more than the person that’s going through it.” Casey, 48 years NSW



“[What would really help partners to understand better would be] some kind of education, like seminars, like ‘Living with a partner with a chronic disease’... Getting them to breathe through a straw... If they can understand the feeling they can understand everything that goes with it, I think. You would then understand that things are limited, people can’t do this and they can’t do that so the expectation’s not there, and not to be blasé.”  
Stephanie 38 years NSW/ACT

Interviewees also felt that the general public had poor awareness of the impact severe asthma had on their lives and they felt that this should be addressed through public education campaigns.

“I think [severe asthma] needs a bit more publicity. Because when you say to people ‘I’ve got severe asthma’ I think 90% of the population goes ‘Oh yeah, asthma. Every second person has that.’ I don’t think there’s a comprehension there.” Stephanie, 38 years, NSW/ACT

## Regional and rural Australia

Australia is a large country and patients living outside major cities struggle in many ways to access care. Access issues include the need to travel hundreds of kilometres to a specialist appointment, and when using poorly integrated public transport, this increases the travel time, cost (e.g. overnight hotel stays may be required) and the physical effort of attending appointments. Travel reimbursement is limited to only certain travel costs and patients tend to be unaware it is available unless financial problems are disclosed to their specialist. There is poor or limited communication between city and small regional hospitals and treatments prescribed by city specialists may not be familiar to rural specialists who react by wanting to change the prescribed treatments. There are additional logistical difficulties in organising particular tests and obtaining drugs prescribed by city specialists at the patient's rural location, often because the expertise needed or the drugs prescribed are not available locally.

“It all comes back to the communication. If you get a treatment in a city hospital that needs to be transferred back up to your country hospital. And if it's a drug they don't understand at least they [should] be contacted [by the patient's city specialist to encourage local doctors to say] 'I'm not taking her off that [treatment] cause this is what they've done with more knowledge [in the city], so they stay on that'. I can't get a lot of them the medications up here unless it's ordered in.”  
Casey, 48 years, NSW/ACT



With respect to primary care, in rural locations there may be more limited understanding of appropriate treatment for severe asthma.

“You've just got to try and educate some of these [GPs]! Sometimes you can just explain to them 'Well, if you look at my records I have this, and this, and this is what usually happens'. I had one and he actually said to me 'Look, anyone else I wouldn't recommend antibiotics'. But he said 'Looking at your records I think it's safer just to do it'. Some you just walk out of there thinking 'Why did I even bother?' Because you've just got nowhere and you might as well have hit your head against a brick wall.” Nancy, 51 years, TAS



For patients who have lost so much in their life due to the limits imposed by severe asthma, moving to the city to improve access and quality of care was understandably unpalatable.

## Medication use

While many people with severe asthma considered their medications effective and necessary for managing their asthma now and in the future, there were often substantial downsides to treatment which could become barriers to adherence. Some patients doubted the efficacy of treatment to the extent that they considered or wished to reduce or stop treatment. Others did not take treatment on days when they felt well for different reasons, including wanting to 'feel like they didn't have asthma' or to reduce overall medication cost. Total monthly medication costs, including those for other conditions, could be as high as \$150 which resulted in some patients refusing what they considered to be non-essential treatment.

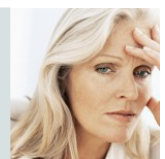
"When I do take them I take them correctly. But then if I'm having a good day -and this is really bad what I'm going to say - because if I feel good and all the rest of it I think 'I'm not going to take them today.' And that's one I don't have to pay for, do you know what I mean?" Joy, 50 years, SA

"I struggle with it, the medication. With the introduction of all these other medications, a lot of them aren't on the PBS. And yeah I've actually refused the bone one because on top of taking the asthma one and paying for everything else and travelling it's just unaffordable. I've got to eat. [It's] probably around \$120, probably more than that [per month]." Casey, 48 years, NSW/ACT



Side effects of treatment in severe asthma could be substantial and debilitating, particularly for those on high dose oral corticosteroids. Such serious side effects included Addison's disease and bone problems, such as avascular necrosis, which has serious additional implications for the patient's quality of life. Most patients appeared to balance the downside of these serious side effects against their necessity.

"Because of the high doses of cortisone that I've had for the asthma...my neck's all giving way and the nerves are getting pushed on by where the discs are giving way. So, that's causing all the pain in my shoulder and causing pins and needles and numbness in my arms. So I'm struggling with the use of my arm...[But] I look at it that: if I hadn't taken [prednisone] I wouldn't be here." Nancy, 51 years, TAS



But some patients became so frustrated with the side effects of steroids that they stopped them without prior discussion with their doctor, with serious consequences for their health. Larry, for example stopped all steroid medications due to dismay at the side effects of long-term daily oral steroid use (e.g. damage to joints, bones, teeth, eyes) and this led to a near-fatal asthma attack [see box].

“I'm getting cataracts, and I'm getting necrosis in the hips, my skin's thinning down, my dental health's gone down just completely and all my beautiful teeth started falling out. All these side effects um, started accumulating. And it's all because of the steroids... I've only had 2 hospitalisations...The one was the respiratory arrest and that came about because I was a bit depressed about all the steroids I was on, so I stopped taking them.” Larry, 54 years, NSW

Several people described over-using Ventolin, with some using as much as one Ventolin inhaler per week. This was driven by different reasons in each individual from habitual behaviour, wanting to self-medicate without seeing a physician due to the demands of a busy life, or fear of frightening asthma attacks that were perceived to be combatted by 'life-saving' Ventolin. These hidden beliefs are very risky and they are rarely talked through with a health care professional.

“I don't really tell the GP how much I take as far as the Ventolin 'cos I go and buy that myself across at the chemist... I just buy from different chemists so they don't sort of think I'm coming back and using too much...I don't talk about that [with my specialist]. I mean he did ask me once last time I saw him there 'Why do you take so much?' I said 'Fear! Fear, Dr X!' ((Laughs)). That's all we said. But I don't know if he knows what I'm saying or if he appreciates what I'm fearing.” Kenneth, 51 years, TAS



## Experiences of primary asthma care

People with severe asthma reported diverse care experiences in general practice settings. Some described accessible, skilled GPs, with whom they had a good rapport, and could discuss both their asthma and how they cope with it in their daily lives.

However for others, their experience was the reverse. GPs were poorly accessible when their asthma worsened. There were important gaps in their GPs' knowledge about the risks of severe asthma and its appropriate management. Further, communication could be very limited, with a GP simply typing on a keyboard throughout the appointment, or clumsy, with the GP responding insensitively to the patient's comments about the upsetting limitations severe asthma places on their lives.



“Because one of the things [my GP] said was ‘Oh I didn’t know people with severe asthma had to have long-term steroids for their lungs to get back to being in a reasonable state.’ And I said ‘Oh!’. She said ‘I thought the treatment was a high dose quickly for 3-5 days and then you stop and then everything would be fine’.” Cheryl, 53 years, WA



“I think it’s very, very hard to discuss how it comes between you and your partner. For instance I can remember trying to raise it with the GP and I said ‘Oh well, you know, my husband has told me that I move the bed every night to the point where it bashes into the wall with my breathing.’ And he laughed! And that was the end of the conversation! Well, if he’d said to me ‘What does that mean to you?’, and ‘How would you like to see that changed?’ and “Does that worry you?” or ‘And how does that come between you?’ Anything! But to laugh at me was like dismissing it and not validating it as a problem!” Rhonda, 54 years, NSW/ACT

## Experiences of secondary asthma care

The majority of patients described their specialist as professional and knowledgeable and expressed trust in their specialist's decisions. Many patients described a good rapport with a supportive specialist who made time to listen to their perspective on asthma management, and its effect on their daily life.

On the other hand some patients felt uncertain if asking a question was acceptable to their specialist, appointments felt rushed, and specialists dominated the interaction leaving little time for the patient to express their views. Ineffective communication skills were sometimes reported with doctors repeatedly "telling off" about poor adherence or failing to explore the barriers or concerns driving patients' medication-taking decisions.

On a practical level, cost of appointments, cost of hospital parking and a long delay in getting a first appointment in busy specialist clinics were barriers to accessing care.



"I would say that uh, he would lead 80% of the uh, appointment and I would have a very minor role. That's because he's got tangible proof and to me, mine is only probably an emotional response...I mean, if we were just having a general conversation about my health I would like to discuss options. I would like to make it a say 60-40. He's got the tangible proof. I haven't. But I would like to put forward some ideas myself as well." Keith, 64 years, VIC



"[My specialist] said, you know, 'Cut down on this and cut down on that. Use more preventative'. You know. But [I thought] 'Oh god. Not again. Here he goes again' you know ((laughs)). I've heard it before from him and he just tells me the same old thing. Oh I've probably been going for 10 years. I've been seeing the same specialist anyway there. And um yeah, I probably don't like going to see him for that reason too." Kenneth, 64 years, NSW/ACT



## Experiences of asthma flare-ups

People with severe asthma experienced frightening symptoms during asthma flare-ups (attacks). These were sometimes treated at home but others required emergency department (ED) visits and hospitalizations, with some patients being admitted to hospital more than once per year. Some attacks were near-fatal and required intensive care and long recovery times. Hospitalisations prevented people with severe asthma from taking care of their children or fulfilling other responsibilities.

Asthma attacks were sometimes very frightening or traumatising for the children and family members of people with severe asthma.

In the lead-up to a severe episode, many patients reported difficulty perceiving that their asthma was deteriorating and being indecisive about when to go to ED. Some took extreme risks by avoiding ED due to work or family commitments or a desire to prevent disruption to their life.

“You just cannot breathe. It feels like your lungs are full of water. It feels like there’s no oxygen in the air and it’s so tiring and you just wonder whether you can take the next breath.” Jacinta, 63 years, NSW/ACT

“You start to think ‘Gosh I’m going to die here maybe’ because you can’t breathe. It’s a terrible, terrible sensation when you’re trying to breathe and you can’t. And you’re coughing, and the coughing is blocking the airways and you try to suck in a bit of air and, and it’s frightening.” Kenneth, 64 years, NSW/ACT



## Emergency care

Almost all people with severe asthma reported high quality paramedic, emergency department and in-patient hospital care. However there appears to be a lack of continuity in acute asthma care in different hospitals with patients reporting large differences in treatment steps from hospital to hospital.

Some one-off experiences highlighted the need for improvement in certain institutions and individuals. For example, in a small rural hospital, staff struggled to make decisive treatment decisions when treating Casey (48 years) who had undiagnosed severe asthma at the time of her severe asthma attack. In another, Larry reported a physical struggle with a paramedic who forced him to lie down during a severe asthma attack.

While some interviewees were satisfied with current approaches, other patients felt that emergency department staff were unaware of, or failed to acknowledge how frightening an asthma attack can be.

Suggestions for improvement included using more empathy and reassurance and taking time to listen to the patient's wishes and wisdom about their own asthma during ED care.

“I know they're rushed and, and everything else [in ED], but for 2 seconds it doesn't take long just to put your arm around the patient and say 'It's all going to be ok. We're going to sort this out. Everything's fine'.” Joan, 52 years, TAS

“I said, you know 'I'm not good.' [And the ED staff said] 'Oh you'll be right!' and everything. And 5 minutes later they had me in one of those resus things trying to resuscitate me! And I collapsed on the chair. And so I think they need to listen to the patients at times too. Because sometimes that, you know, you might look okay but you know yourself most.” Nancy, 51 years, TAS



**Practical suggestions made by patients for supporting emergency care included:**

- Suggesting an asthma bracelet for people with severe asthma, for quick identification if they become ill in a public place.
- The introduction of a personalised emergency treatment protocol, listing, for example, the specialist's current treatment decisions and recording the emergency treatments which have been effective in the past for this patient.
- Training on breathing and relaxation to support patients to control panic during periods of worsening symptoms or attacks.
- For patients with the most severe asthma or during symptomatic periods, it may be beneficial to provide a text messaging support programme, similar to Asthma Assist, which would allow patients to seek advice when they are too breathless to speak on the telephone.

# Recommendations

We call on national and state policy makers, health authorities, allied and health care professionals, consumer organisations, patient support groups and employers to work together in relevant ways to:

- Identify and manage the mental health and emotional support needs of people with severe asthma, particularly those living alone.
- Provide life planning counselling, perhaps via a telephone support line or face-to-face, to assist people with severe asthma to manage the complexity asthma adds to parenting, relationships, work and financial issues.
- Provide support for the children and family members of people with severe asthma to deal with the emotional and practical impact of caring for someone with severe asthma.
- Foster the belief of patients, and those that support them, that a clear understanding of their condition and treatments is their right, and that time should be set aside in medical appointments to articulate their questions and concerns, and have them answered sufficiently.
- Optimise knowledge on severe asthma care in general practice, out-patient and in-patient settings to ensure patients are managed safely and effectively.
- Improve communication between specialists and GPs about their patients with severe asthma.
- Improve access to good quality primary and specialist care for patients in rural locations.
- Educate the general public on the specific burden and risk of severe asthma, and what support they can provide in an emergency.

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