

SUPPLEMENTARY MATERIAL

A1: Standard criteria for assessment of severe asthma

A confirmed diagnosis of asthma; need for high dose inhaled corticosteroid (ICS)/long-acting B₂-agonist (LABA) despite good inhaler technique and adherence; poor asthma control (e.g. Asthma Control Questionnaire score consistently >1.5; two or more exacerbations requiring oral corticosteroids within the previous year; one or more hospitalisations due to asthma in the previous year, and/or persistent airflow limitation).

A2: Semi-structured interview guide

Topic	Question
Describing your asthma	<p>If you had to choose one word to describe what having asthma is like for you, what word would you choose? Can you describe in as much detail as possible an experience with asthma that fits this word?</p> <p>Are there things you'd like to change about your asthma? What are the most important ones to you?</p>
Impact of asthma on quality of life	<p>On a scale from 1 to 3, to what extent do you feel able to do the things you want to do in your life? [1=I can do everything I want to do / 2=I can do some of the things I want to do / 3= I can do few of the things I want to do.] What made you choose that answer?</p> <p>When you compare yourself to people you know who <u>do not</u> have asthma, do you notice any differences?</p> <p>How do you think people without asthma see people with severe asthma?</p> <p>Does your asthma have any effect on the people around you? Who/in what way?*</p>
Day to day management of asthma	<p>Can you tell me a bit about (other) things you do to take care of your asthma (other than taking medicines)? Are there things you have been advised to do to take care of your asthma that you can't get around to?</p>
Experience of severe asthma exacerbations	<p>Can you describe in as much detail as possible, the most severe worsening of your asthma that you have experienced? What happened after your asthma [flare up]? How long did it take before things were back to normal with your asthma? Once your asthma was back to normal, did the [flare-up] still affect you in any way?</p>

*After the initial 4 interviews, two new questions were added to the interview guide "Describe the asthma symptoms you might experience on a typical day and night" and "What were your experiences of asthma as a child?"

A3: Symptom patterns experienced by patients with severe asthma

Quote	Description
<i>"I'm running out of breath. I'm very restricted and tight in the chest and it doesn't feel like it's going anywhere. Depending on the day, it could be 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."</i> Casey, F, 48 yrs.	Daily, severe symptoms
<i>"I'm talking every couple [of] weeks, I was having sudden-onset asthma attacks that would come without warning. Sudden upper airway bronchospasm almost like an anaphylaxis but it was actually my asthma, where I'd just sort of not be able to breathe at all."</i> Alice, F, 23 yrs.	Sudden-onset attacks
<i>"Some days I'm quite fatigued and other days I can get up and do things and I'm alright...I can do a walk some days and other days I really struggle to get to the end of the street."</i> Brenda, F, 53 yrs.	Good and bad symptom days
<i>"I go to bed and I probably wake up at about 4 o'clock and quite tight in my chest. And just that feeling like someone's sitting on you... So I have a puff on my Venty [sic] and maybe doze back to sleep. Then when I get up, I still feel quite often like I've got a lot of stuff in my lungs."</i> Cheryl, F, 53 yrs.	Nights interrupted by symptoms
<i>"I can go out of the house in the summertime no problem. Start walking with my wife no problem. In the winter time I have that double handicap you might say: the cold air and the exertion...I just get that sudden tightness in the chest."</i> Keith, M, 64 yrs.	Seasonal differences in asthma

A4: All theme and sub-theme quotations

Theme: The body as a hindrance

Personal hindrances

Physical: *"Most housework I can't do. Can't vacuum, I can't do the bathroom or anything like that."*

Nancy, F, 51 yrs.

Spontaneity: *"Running around the oval after my little boy. I have to stop, take some medication, give it 5 minutes then chase him. I can't just go 'Let's go now!' you know."* Stephanie, F, 38 yrs.

* Independence: *"I'm very, very tired. I've got my daughter coming over cause I'm finding it hard to do the housework...My husband has got to 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. And I just feel hopeless because I feel like I'm a cripple...[I'd like to] enjoy my day, being able to do the things I can't do, and not having to depend on anybody."* Katherine, F, 59 yrs. *

Interpersonal hindrances

* Socialising: *"I'm a very social person. I'd like to go out all the time and meet with friends and I have to say 'sorry' last minute 'I can't go because I have asthma'."* Rebecca, F, 45 yrs. *

Socialising: *"People are offended if you say you can't come to a dinner...I guess it's fair to say there's some friends who won't ask me to things [anymore]."* Paul, M, 62 yrs.

Relationships: *"He loves camping but I can't go where you can't get phone reception. And the sex [is unattractive due to shortness of breath]...And yeah that relationship, it's gone to crap [sic]."* Casey, F, 48 yrs.

Parenting: *"When my kids were young I really couldn't play with them all that much."* Larry, M, 54 yrs.

Extrapersonal hindrances

Career choice: *"I was knocked back [from nursing] due to my asthma. And that would probably have been the hardest thing because it was the only thing I had ever wanted to do."* Nancy, F, 51 yrs.

Career discontinuation: *"There comes a point where you can't do the job anymore so you've got to get out of there and let someone else do the job."* Larry, M, 54 yrs.

Emotional distress

"It's frustrating, upsetting. There's things I really wanted to do and I haven't been able to do...It does make you depressed, because people don't see the sickness that has happened over my life." Brenda, F, 53 yrs.

* *"I feeling that shortness of breath as a result of the exertion...it's frustration that leads to annoyance and I just get annoyed with myself. And to a certain extent I become a little anti-social I suppose. I don't want to talk to anybody or hear anything."* Keith, M, 64 yrs. *

"On some occasions the mind's there and wants to do it but the body can't keep up...and it sort of makes you feel worthless in a way." Neil, M, 60 yrs.

*Quotation not included in text of main paper

Theme: Burden of treatment

Ambivalence about treatment-taking

Accepting it: *"Um well, you'd probably be better never taking anything but that doesn't work. So if I need to take it I take it... If you don't you'll end up being quite sick and you'll end up in hospital so you don't really have much choice."* Linda, F, 65 yrs.

Disliking reliance on it: *"I mean having to be reliant to take the medication [is something I'd like to change]. I mean number one it's reasonably expensive, um, I suppose the fact is I've just accepted that it's one of those things, but it would be nice not to have to take anything...it's a lack of freedom I suppose, you know."* Cynthia, F, 51 yrs.

Time-consuming: *"Well I know they work but really, it takes so much time to take it all. You just wish that [medicines] were combined ((laughs)). You know, if, even just two of the sprays, if they could just combine those and then the other two combined as well...I don't know, I'd just be a freer agent I guess."* Jacinta, F, 63 yrs.

* Inconvenience of appointments for injectable biological treatment: *Well you have to go to your GP 'cos there's a risk of anaphylaxis. Um, so you've got to be there, And I've got to have a bloody EpiPen in my bag every time I go there in case I have a reaction. Yeah, it's a bit of a cumbersome kind of system. Um, my GP, it's a bit of a drive for me and I've gotta put away, basically put 1 day aside virtually every fortnight to go and get this all done."* Larry, M, 54 yrs. *

* Disliking how it takes over life: *"You feel trapped. You do, you feel like you're ((sigh)) a slave to it. You're a slave to this regimented ordeal you've got to go through every day. 'Don't forget to take this [treatment]' ((bored voice))."* Larry, M, 54 yrs. *

Oral corticosteroid adverse effects

Concern about future severe side effects: *"I'm thinking I'm probably going to get side effects from the cortisone. The worst thing is you know, you get osteoporosis and I can just fall over or something and break a hip."* Pamela, F, 60 yrs.

* Concern about current and future severe side effects: *"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. Eh, all these side effects um, started accumulating. And it's all because of the steroids...then of course the most scariest one for me was the fact that the gland that produces your natural corticosteroid after extreme long-term use can, can atrophy and wither away to nothing and then your body can never produce enough natural steroid ever again."* Larry, M, 54 yrs. *

Concern about very severe side effects: *"I've just been diagnosed with Addison's disease recently which is my adrenal glands have shut down. So that's from the use of steroids...Addison's disease is like, it's all your hormones in your body and, like it can cause you to have inflamed joints. They did say that because of the Addison's my appendix is flared up and I've just had [it] removed just 2 weeks ago. So you don't have that ability to fight things, infections. If I cut myself, wound healing takes a lot longer...I get quite fatigued and all that sort of thing."* Brenda, F, 53 yrs.

Concern about changes to physical appearance: *"I just came off the Prednisone and the pictures are not flattering. I'm embarrassed [about the weight gain] 'cos I can see that I'm so puffy."* Rebecca, F, 45 yrs.

*Quotation not included in text of main paper

Theme: Alone with asthma

Being misunderstood

* Few understand: *"When you can't breathe you can't breathe, and people don't understand what it's like unless they have [experienced it]." Nancy, F, 51 yrs. **

* Exaggerating (invisible) asthma: *"[People [say things like]: 'Oh, but you look really well'... And it was like [they felt] I was, not fabricating it, but it wasn't as bad as what the doctors and my body was actually saying." Brenda, F, 53 yrs. **

Confusing severe asthma with fixable milder asthma: *"You have all these ads on telly with wonderful Australian cricketers that play world class cricket, and they take their puffer. 'We have asthma but we can do anything'...[People think] 'So why can't you do that?'" Pamela, F, 60 yrs.*

Resentful partners: *"He's resentful of it. Sometimes I wonder if he really thinks I'm that sick at all, and I know he doesn't understand." Stephanie, F, 38 yrs.*

Emotional distress: *"I have struggled with [depression] personally when I have been so, so sick, and I probably struggle with it every day now that I live alone. It's harder ((becoming emotional))." Rhonda, F, 54 yrs.*

* General public education to address misconceptions: *"I think it 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. And you don't want it as a sob story, but there needs to be that acknowledgment that people with severe asthma are [not mild] asthmatics... And it doesn't just affect the way you breathe, like, there are so many other things that are affected. I've got a pace maker because I got an irregular heart beat from too much Ventolin. And I've got avascular necrosis because of too many steroids. ((Laughs)) And all these things that can be associated [not just] 'Oh, you've got asthma, you just can't breathe well.'" Stephanie, F, 38 yrs. **

Stigma and disclosure

Insensitive comments: *"I went to a musical with a friend...she turned to me and said 'How on earth did you hear any of that? You were wheezing louder than the choir'... I felt 'Gee, well, where do I fit in? Where is my place? Where am I supposed to be?'" Rhonda, F, 54 yrs.*

Concealing asthma: *"I don't want to be specialised at all in their eyes, or treated in any different way because I've got asthma." Steven, M, 71 yrs.*

Disrupted identity or self-concept

* Social identity: *"I'm thinking 'No, I'm coughing too much this morning, I'll put [having coffee with my friend] off.' So I'll make some excuse, and that's not, I don't like doing that. I feel false." Barbara, F, 71 yrs. **

* Social withdrawal *"I'm not introverted. I'm fairly a little bit more the other way actually but [asthma] does make you introverted. You know if you can't breathe, it's hard sometimes to even, I mean, I don't even like having conversations." Jacinta, F, 63 yrs. **

Dissociative thoughts: *"[Asthma] isolates you because inside there's an emptiness or a difficulty with trying to balance with who you really are and what you need to be...It's like trying to avoid yourself while maintaining some sense of self." Rhonda, F, 54 yrs.*

Alone with exacerbations

Panic, fear and anticipation of death: *"Suffocation. Can't breathe. Dying. No other way to put it...Trying to control my breathing, panicking at the same time because I can't breathe and [thinking] am I going to see the night through?"* Neil, M, 60 yrs.

Use of cognitive breathing/relaxation strategies: *"Even if I have to lay on the bed and just settle, relax, try and breathe, and get it out of my head that it's my last breath because that's what panics you."* Joan, F, 52 yrs.

* Overuse of reliever: *"Ventolin, I can do sometimes 6-8 puffs. Oh just when I'm starting to feel a bit of shortness of breath and that I'll take it just as, you know, security sort of, to get me through the day and make sure I can still breathe without having any worry of 'Will I have an attack if I don't take it?'"* Raymond, M, 50 yrs. *

Habituation/poor perception of symptoms *"I can cope quite well with very little output if you know what I mean. So you adjust to that level. And you don't really realise how bad [your asthma] is until someone points it out to you."* Stephanie, F, 38 yrs.

* Shock at the proximity to death: *"I could have actually died that day and that was a bit of a reality check. It's like 'Wow!'"* Joy, F, 50 yrs. *

* Emotional disorder after exacerbation: *"[My exacerbation] took the wind out of my sails. I felt sorry for myself for well over a month."* Cheryl, F, 53 yrs. *

Family member's trauma: *"I think it has changed the way [my son] has turned out because he's sort of a bit of an anxious character now because he saw some terrible things happening to me and he panicked and thought you know, 'I'm going to lose my mum'."* Jacinta, F, 63 yrs.

* Emotional support for family: *"I think [my kids] thought I was going to die and I didn't have a husband or anyone to be there with the kids ((becoming emotional))."* Rhonda, F, 54 yrs.*

* Responsibility for exacerbation occurring: *I guess some of my friends have been like that too. You know if I have an asthma attack sometimes they believe that I could have prevented it. [They say] "Oh you silly thing what did you do that for", that sort of thing. And all you really want is, [to] get better"* Jacinta, F, 63 yrs. *

*Quotation not included in text of main paper

Theme: Striving to adapt

Adjustment to life with severe asthma

* Good adjustment *"Asthma doesn't dominate my lifestyle. It's part of who I am."* Paul, M, 62 yrs. *

* Poor adjustment: *"[It's] crap [sic]...[Asthma] affects every hour of every day of every week of every month of every year of my life. It's affected my occupation, it's affected my family life, it's affected my future, like my ability with having a family. It's changed everything. I can't really think of much it hasn't changed."* Stephanie, F, 38 yrs. *

Acceptance of severe asthma

* Accepting severe asthma: *"Yes I do consider [my asthma] severe. It's certainly debilitating and frustrating. Um I hate the way that it rules or has so much control over my life."* Neil, M, 60 yrs. *

* Accepting asthma but not severe asthma: *"Look to be honest I see myself as an asthmatic but I don't see myself as a crippling asthmatic. Compared to others I suppose I am, but I personally don't see myself that way...To me a severe asthmatic is someone who spends at least 1 or 2 days a week in hospital. You know. I don't see myself in that category".* Keith, M, 64 yrs. *

* Denying asthma: *"Because it's just too hard! It's like, I don't want to have [asthma] so I won't have it, but I have got it, that's just how it is. Just not accepting that I've got it I guess."* Joy, F, 50 yrs. *

Positive coping strategies

* Accepting my disease: *"You can't say 'I dislike having asthma'...I don't hate it, I don't mind it, and it's just a disease, everyone has different diseases."* Raymond, M, 50 yrs. *

Acquiring self-management skills: *"It wasn't really until I had a full asthma plan working closely with a specialist, which is now many years ago, that I was actually able to get all those things under control".* Paul, M, 62 yrs.

Managing emotional problems: *"Stop wallowing in self-pity basically...Try and camouflage it with something else...Like I might go out. Get out and walk the streets, and look in shop windows."* Larry, M, 54 yrs.

* Planning to achieve: *"When I went back to Uni. everyone said 'Oh, how are you going to do that?' It took me 6 years instead of 4, but I finished it...It's about planning to achieve rather than working within the limitations that others place on you."* Rhonda, F, 54 yrs. *

Switching to doable activities: *"I do exercise with people who know my limitations and they don't care if I stop or whatever...Yeah, I don't make myself do [things] that make me really wheezy... I just don't put myself with those people that run their 42km marathon because I know I couldn't do something like that."* Cheryl, F, 53 yrs.

Negative coping strategies

* Denying my disease: *"Because it's just too hard! It's like, I don't want to have [asthma] so I won't have it, but I have got it, that's just how it is. Just not accepting that I've got it I guess."* Joy, F, 50 yrs. *

Pushing through: *"Being in a state where I probably should've been in hospital because my lung function was that bad... having to get it done because the guy standing next to you is perfectly healthy ... and you've got to keep up with him."* Larry, M, 54 yrs.

Risk aversion/exertion restriction: *"Like this morning I had to go to the eye specialist ... which is not far, over the road actually. I thought 'Will I walk? No I'll drive because I might get out of breath'."* Gloria, F, 81 yrs.

Vigilant monitoring of symptoms: *"I am so in control of my asthma now I do not let myself have an attack. If I get the slightest inkling that something's happening, I am onto that nebuliser like you wouldn't believe!"* Jacinta, F, 63 yrs.

* Habituation and/or poor symptom perception: *"A lot of things I don't even notice it, but if I'm talking to someone at times like family that know me, they'll say "You're having problems with your breathing today."* Nancy, F, 51 yrs. *

Childhood experiences

* *"I avoid doctors like the plague. Because I've seen so many of them I guess. When I was a kid, every time I saw a doctor they'd whack me in hospital. So maybe that's got something to do with it. 'Cause you know it was pretty horrible. I can remember once when I had an asthma attack, um, and they tied me flat on the bed... I mean that was just horrific for me because I just couldn't breathe!"* Jacinta, F, 63 yrs. *

Concerns for the future

* My health may stay the same or improve: *"I'm really hoping [my health] either stays the same or we can get a little bit of improvement. I don't see that, but hopefully we don't deteriorate."* Joan, F, 52 yrs. *

* New comorbidities may emerge: *"Well, probably I will have osteoporosis because of my, um Prednisone intake. I'll probably walk around like a little old lady."* Linda, F, 65 yrs. *

* I may die earlier: *"I'm slightly concerned that my longevity mightn't, that I might die of a lung associated disease, um and I'd prefer not to."* Steven, M, 71 yrs. *

* New therapies offering hope: *"Well there's always new things coming up or around the corner isn't there? Like this [omalizumab]. I think it's helping me...I suppose in years to come they'll probably may have found a complete cure for [severe asthma] ...I think they'll have figured it out in another 30, 40, 50 years, I'm hoping, but I won't be around to see it ((laughs))"* Pamela, F, 60 yrs. *

* Health costs may become unmanageable: *"I don't expect it will get any better. And with ageing it will probably get harder, and that is not a very nice thought. And I've already worked out that the day I stop working and can't financially support myself I should be as good as dead because I can't afford to maintain this illness without working and having a good salary"* * Rhonda, F, 54 yrs. *

*Quotation not included in text of main paper