

SERVICES, SUPPORT AND SYSTEMS > CHILD ADOLESCENT & FAMILY SERVICES (CAF) > INTERACTING WITH CAF

# Interacting with CAF

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## 1. Introductions - The process of accessing an assessment

Well, hi, I'm Dr. Valerie Black and I'm the clinical director of the CAF service and I've worked in the in-patients and out-patients and been working there for quite a long time. Hi, my name is Shelley and I'm a parent of neurodiverse kids and I am also neurodiverse and I'm here today to ask some questions about the process of accessing CAF. The first question I wanted to ask is, my husband and I have been to the GP and we now have a referral to CAF. What's the process next, like how long will it be before we're notified and how will we be notified by CAF? So, when a referral comes in, it comes to a group we call CAF Link and they triage all the referrals.

So, you might find that they ring you to get further information to help them make a decision about the referral. And then, if they accept the referral... ..then your GP will be notified within a day or so. And then the referral is passed on to the team that will treat the young person and so you'll then get a letter within a couple of weeks letting you know that your child is on the waiting list and how to access a number of supports. So, if I haven't received a letter, how long should I wait and then who should I contact? I'd wait a couple of weeks and then I'd contact CAF Access. From when the first referral's been made?

Yeah. Excellent. Can you decline my GP referral? Yes, yes we can. And sadly we have to decline a lot of people that are referred because otherwise we'd have a wait list of five years. So, we do have to do that. And we always try and think quite carefully about what services in the community would be relevant for that young person. So, we'll always give the GP a list of recommendations of other services that they could potentially go to. So, it would be always worth, if you haven't heard anything, checking in with the GP if the referral has been declined, what CAF recommended. And if I felt that it should have been accepted, can I ignore that recommendation and just ask him to re-refer?

You could do that. But probably... Probably if nothing had significantly changed, the CAF service would say, please ask them to do these recommendations. If we do the recommendations and nothing improves, can we ask to re-refer that one? Absolutely, be referred back, yes. So, most of the young people who are accepted by CAF have done some work in the community before they are accepted? Once we have made it on the wait list and we have a letter, how long? Well, that's a really difficult question to answer because there is quite a significant wait list, which is really quite distressing for us that we have that big wait list because unfortunately every week way more people get referred than we can see.

So, it kind of depends. If it is like, for example, ADHD and there aren't major risk factors, you can wait quite a long time, up to say around eight months or so. And if it's more urgent, more significant risk factors, then we triage them as we go. If I can access private mental health for my child because I know that that service is also extremely stretched and I'm on the wait list, will I be thrown off the wait list or can I just wait until we get to the front of the wait list and then just go public from there? Yes. Obviously, if you can access private mental health support, then that's fantastic because obviously it is really stressful for people sitting on the wait list.

When your appointment comes up, obviously disclose that information and then there can be a discussion. I mean, if the private help has been really helpful, you might decide that you don't actually want to come to CAF and you might decide to decline that appointment. Or it may be that actually, then you want to transfer over to CAF. And we're very mindful that private mental health care is very expensive and it's a huge financial stretch for many families and they might be able to afford it for a short period of time but not for the amount and course of treatment that's required. That's reassuring.

Is the phone call at the start part of that triaging? Yes. So the phone call at the start, not everybody gets a phone call because sometimes at the very start, because sometimes the referral is very clear and it's very obvious it needs to be accepted and it will go through. If there's concern about risk issues that have been identified or if there's any things that the team that are making the decisions about accepting or declining feel they need to ask more about to make a good decision, then they will go in and talk to the family.

## 2. Supporting my child during the process

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Sometimes my son can become distressed and on occasion he's become unable to manage it, like a little bit rough, violent. If he becomes seriously dysregulated, what can I do? It kind of very much depends on the age and the stage and the developmental level. Obviously if somebody's presenting with really serious violence, like going to stab someone or something like that with a knife, then the first thing to do would be to exit everyone safely who can be exited from the environment. So make the environment as safe as you can and in those kind of scenarios it would be best to ring the police where there's imminent risk of danger.

If it's not to that kind of level, you may require some support from other people. So you might want to ring a trusted friend or a relative that you know is really helpful. Yeah. It could be if it was kind of quite a violent kind of situation and you weren't sure how to handle it, you could potentially ring the CAF emergency service and they might be able to give you some advice as well. Generally it's hard to make those kind of decisions in the moment and it's useful to have thought through a plan or talked through a plan when things are reasonably settled so that you and your child kind of know what you're going to do if that kind of scenario kind of happens.

Unfortunately sometimes my son can become really upset and he's even been known to hurt me or his siblings. If I became really concerned, like it's worse than it's ever been, what are some of my options? I think that, you know, if you're on the waiting list and this is happening, it will be really important to ring and let people know it's happening. And they may be able to get a little bit of advice on the phone. If this situation is actually people are at serious risk of being hurt, it is okay to call the police. Your child is not going to get, you know, charged and is not going to have legal long-term consequences if you do that.

It's very, very rare for police to charge anyone under the age of 14 unless it's an incredibly serious situation. So the reality is they can help come and de-escalate the situation in really urgent and emergency situations. And it does put a little bit of a clear message to the young person that actually it's not okay to be, you know, punching your mother or, you know, smashing TVs or, you know, stabbing the door. You know, it's not okay. So it is a helpful message for them as well. And how young are we talking about? Well, it's situations where you as a parent feel really unsafe and feel that someone is going to get hurt.

The age of the child isn't quite so relevant because some children at even quite young ages can be very, very violent. It's the risk that you are perceiving. Can CAF help? Can they come out and help us? Unfortunately, no, we don't have any ability to do that. So you could get some advice on the phone if you're in the team. No, we can't do that by the duty worker. Otherwise, no, I'm sorry, we can't do that. What signs can I be looking out for to assess the risk that my child faces around hurting themselves or others? Yeah, that's a really good question because sometimes it's really hard for parents to tell because sometimes young people keep that information really close to their chest and don't always share it.

So the most important thing you can do is to try and keep the lines of communication as open as you possibly can. Okay. So hopefully they will tell you if things are getting worse. But other things that you could kind of look for would be things like they're increasingly withdrawing, they're cutting themselves off from their friends, they're stopping doing things that they normally would enjoy, they may be researching ways to harm themselves online, they may be giving away things that are really important to them, to other people. You may even find a suicide note. Yeah. It would be all kinds of signs that the situation is getting more serious and that they would definitely be worth ringing and alluding the team to.

If my child has said that they want to kill themselves right now, and in fact they've said it every day this week, how seriously should I treat them? I think it's really important to talk to them about it and try and find out what you can. Sometimes there's really obvious reasons that young people want to kill themselves. Sometimes there's really obvious reasons that young people want to kill themselves.

I think it's really young people saying things like that like they've been bullied at school or they've just broken up with their boyfriend and there might be some really practical things that you can do to support them but clearly i think if they're repeatedly saying that that is something that you do need to run the team and talk to them about it may be that their appointment needs to be brought forward how long after i've been accepted to be on the waitlist should i wait before i contact you to find out why i haven't had an appointment made yet you'll be rung every three months when you're on the waitlist so someone will run who's in the team one of the more experienced clinicians and they'll check out how things are going they'll check if there's any other supports they can suggest while you're waiting they may re-triage where you are on the waitlist depending on the information you know that you give obviously situations can change dramatically some people get better and decide they no longer want to be on the waitlist and other people the situation's obviously deteriorating and they need to be seen quicker so um yeah that's kind of what happens um and you of course if the situation changes you should ring us so in the initial letter you get it'll give you some information about how to contact the service if the situation is changing and you're concerned so definitely ring and and let us know if you're concerned and also it will give you some information about other things that you might want to do like e-therapies or other ngos that could possibly help in the meantime so um yeah definitely ring if the situation is deteriorating

### 3. Getting my child ready for the appointment

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After I'm on the waitlist and I've been notified that an appointment has now been made for us, do I bring my child unmedicated if they are on medication that affects their behaviour or do I tell you the time of day that you can see how they really are? I think you can be confident that the staff believe what you're going to say. So they'll believe what you're saying and we have seen many children who are unmedicated but generally you're wanting to get the very best out of that appointment and get as much information across and all the important information across.

So we would suggest that you leave the child medicated because that way they're likely to, the child themselves is likely to be able to concentrate more and get more out of the interview and you'll probably get more out of the interview because you won't be spending as much time having to kind of try and help manage your child's behaviour. Okay, so if I have a time of day that I know my child is going to be particularly unwieldy, like after school and they're just melting down, can I request a different time if the appointment's going to be incomplete? Yes, absolutely. You could always ring her up.

I mean, we are very busy obviously and there's limited kind of appointment slots so it might not be possible to accommodate you but if you know your child would be way more settled at a particular time, obviously it's in everybody's best interest to try and accommodate that if we can. If my child's really reluctant, to come to the appointment, what are my options then? Ring up and talk to the staff and they may suggest a couple of options. It kind of depends why your child is very reluctant to come. They may suggest that the initial session is a parent session, so you come in and talk about it without the child.

It may be that they think after talking with you that a home visit would actually be the best first approach, so it could go either way. So it's definitely worth ringing and discussing that. The worst comes to the worst and you're on your way and your child won't come. If it's safe to leave them at home with somebody else, then come anyway and then you've started the process.

### 4. Preparing for the assessment appointment

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While we are waiting to be seen, and you were talking about the triaging of urgency, what things can I be doing as a parent during the time that I'm waiting that's going to be useful for me to bring to the appointment? So if your child's had previous assessments, then that's really, really helpful to bring. So, for example, some young people have been to, say, had an educational assessment at, say, Seabrook Mackenzie. That would be a really useful piece of information to bring. If they've been seen by a psychologist or psychiatrist in another setting, that would be really useful information. Sometimes young people have been through the paediatric service.

If it's in Christchurch, we can obviously access through the electronic patient system those notes, so you wouldn't have to bring them. But any other referral, any assessments essentially are useful. IPTs from school, they can be really useful as well. IEPs? IEPs, Individual Education. IEP plans. In the time that we're waiting to be seen, and if my child has had a previous assessment, how would you like us to bring that to the appointment? Like as a physical copy, or if it's electronic, what are my choices? Okay, so if you've got it physical, then that's great. Bring that physical copy with you, and the clinician that you see could ask the administration team to copy it while you're in the appointment, so you can get it back at the end of the appointment.

If you have received it electronically, and it's easy to send it electronically, then just ring the service and ask for an email to send it through. Great. And you mentioned an IEP from school. If I don't have one, is that something I should be asking school to prepare while they're on the waitlist? No, not really. Not unless the school has thought that an IEP is appropriate. If you've got one already, bring it. Or are there any other sort of assessments I should be trying to arrange while I'm on the waitlist? No, I don't think there's anything you need to arrange. No, I don't think there's anything you need to arrange while you're on the waitlist.

## 5. At the assessment appointment

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We've got our first appointment and yay, we've got a date, we're on our way and I'm there. How will this happen at the first appointment? Because I don't want to talk about how horrible my child can be in front of my child at the appointment. What will happen at the appointment? So that's really good if you're able to kind of alert the staff when they start. So basically they'll do introductions first and why you've come and those kinds of things, check their agendas. And if you identify that you would really like some time to speak to the staff by themselves, by yourself rather, then absolutely that would be a really good idea to signal and that will help the staff to figure out how they're going to structure up the appointment.

So for some families, particularly with really anxious children, they'll do the whole initial appointment with the whole family, the parents and the child. For some it's a really good to break it up and often in a first appointment there may be two staff members, so one staff member could go away with the child and play some games for a bit while the parents can talk more about adult issues or things that they'd rather talk about without the child present. And for some, like for older children, it's often really useful for them to have a chance to talk to the clinicians by themselves as well. So it really varies depending on what the needs of the family are.

Okay. And what sort of questions do you have for them? What sort of questions, what will the first appointment be covering? Basically it's a standard mental health assessment and the aim of it is to try and get to an understanding of what the main issues are and a little bit of how they've developed, enough of an idea to start to develop a plan for where you're going to go forward. So they will obviously be asking you about what the current issues are that are most concerning and then they will ask a little bit about how long those issues have been going on for, how they've developed over time.

They'll ask about your child's current functioning in terms of things like sleep and appetite and mood, those kinds of things. They will ask about family history because that can be really, really helpful to know about. They'll ask about the child's medical history, developmental history, alcohol, drug issues if that's relevant. So that kind of thing to get a well-rounded picture and to try and get them to talk about their mental health. So they will ask about that and then they will try and get some ideas about what's really happening. What information will they have before that first appointment?

So they'll have what the GP has sent on the referral and they'll have the information if you've been rung by the triage team, they'll have the information that you've given the triage team. Will they have rung school or anyone else? No. So they won't be contacting anyone else because obviously they need your permission to do those kinds of things. So that will be a discussion between you and the clinicians if they wanted and or you wanted them to collect other information from for example schools or maybe other料 or other people that have been actively involved that you think would contribute to the ongoing assessment and treatment.

They can access your medical records in terms of, if your child's being seen by paediatrics, they can access the paediatric notes. They can also access the prescriptions that have been given. So generally when I see a young person with quite a complicated history, I will usually check if they've had any major paediatric involvement, particularly developmental paediatrics, and if they've got a complex medication regime, I'll often go and have a look at the medications that they've been prescribed so that I'm kind of up to speed with all of that background information. And does that mean that if there have been other assessments that you don't have access to, you would want them in advance as well so that you could review them?

I think it's probably not needed because there's only so much information you can carry in your head at one time. So you want the key back. Okay. background points, if you can, and then you meet the family and you'll generate a whole lot more questions and then when you read those other assessments they'll make a lot more sense to you because you have more of a context to put them in. So I wouldn't feel you need to send them in advance.

## 6. Working with the CAF service

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Okay, so we've had our first appointment. It's all fixed, right? I wish it was that simple. If it was that simple, you probably wouldn't be on our waiting list because, generally speaking, people have tried quite a few different things before they get to see CAF. So, often it's quite a long journey. I mean, occasionally people come with a fairly straightforward ADHD and no other major difficulties and they start on medication and there's some psychoeducation and it can be managed in, say, three sessions. That's definitely the exception. So, most young people come with a much more complicated range of difficulties that take all kinds of interventions, potentially.

So, for example, say, family work, that's going to take quite a few sessions. It might be medication that requires adjustments and dose adjustment. It might be individual work with the young person or maybe work with the parent and the young person together, looking at relationship issues, for example. So, generally speaking, it is a process and some people, as I say, might just be there for three sessions but some people might be in the service for well over a year. So, it's very individualised to what the young person and the family need. But that's really what the CAF service can deliver in terms of, you know.

What therapies or what the experience of a staff is in different kinds of interventions. After the first appointment, what am I going to leave with? So, after the first appointment, the team will feedback their initial thoughts. And a bit of a plan to go forward. So, it may be that after the first appointment is that we need to have another session with the child by themselves you as parents by themselves or we've got halfway through the history but we do need some more so they might initially make a plan to do some more assessment with you. They will always do a safety planning with you so that would be checking like if there's safety issues that there is a good plan in terms of things like medication safe, what's the numbers to ring after hours and hours if you have any concerns, what you might do if you're needing more support so there's those kinds of things.

Your wife will leave obviously with an initial written letter but after you've been seen in the assessments completed an assessment summary will be written up and then you'll be able to go back and see if there's anything you need to do. And then that will be sent to your GP and usually to the family as well almost always. If I get to my first appointment and I'm not feeling like I'm being heard or understood by the case manager and I feel like I just don't I don't get on with them, I don't gel, what are my options? That's quite a rare event, it doesn't happen that often but it does sometimes happen and if it's possible to go back and speak to the case manager and resolve it then that's fantastic.

If you really feel like you can't then you can ring the service and explain that you've really struggled with that person and the manager of the service can have a consideration about well can there be a facilitated conversation, is it a misunderstanding that can be resolved. The CAF service is fairly stretched and sometimes there's not a lot of options in terms of case managers to pick up. If I feel like because of the case manager what they've come up with is just doesn't even represent what I thought we were talking about at the assessment, what happens then?

Generally if you thought that around the case manager you can you can certainly let them know and every case manager is part of an MDT or a team and every young person who comes into CAF has an assigned psychiatrist so for example if you felt that the case manager wasn't kind of getting it you could certainly ask to speak to the psychiatrist and probably what would happen is if the case manager was also feeling like things weren't working well between yourself and them they would probably bring that up at the MDT and then psychiatrists probably hear that and say I need to see that patient but if for example they didn't you could certainly ask to see the child psychiatrist.

Parenting courses, are they still running? So the initial letter will suggest things that you could do while you're waiting that could be helpful so if your child's coming with maybe behavioural difficulties then they probably will suggest that you do something like Triple T, Triple P or Incredible Years while you're waiting so there's a really helpful thing.

## 7. Working with the Paediatric Dept

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One of my children has a primary health complaint, which is not mental health related, and I'm neurodiverse, so within the family is this concern. When he's going through paediatrics, how will he access diagnosis? Well, paediatricians can certainly diagnose autistic spectrum and ADHD, and do frequently. There are arrangements between paediatrics and mental health, and sometimes we have a discussion about which service is actually the best place to see a young person. Occasionally, the paediatrician and one of the child psychiatrists will have a conversation, or the people at Cathlink will have a conversation at the initial referral stage as to which service is the best.

And sometimes people spend... time and development of paediatrics, and then will be referred on to CAF for another piece of work. It just varies individualised. So it doesn't matter where you start? If the primary question is more around autistic spectrum, and the young person's under 14, it's best to start at paediatrics, because it's the best place to make that diagnosis. Whereas if it's more ADHD, it

tends to be CAF that will do that piece of work first. Often... whichever service has them, they may go ahead and do other diagnoses, or they may switch between services, depending on the issues and what we feel is most helpful.

Another of my children is under CAF, and now has a new primary complaint that's physical. What happens then? Well, the primary complaint that's physical, I guess, will be dealt with by the GP and or paediatrics, depending on the name. The CAF service would stay involved depending on whether there's work for them to do as well. So, for example, we do have a number of young people who have physical conditions with significant psychological issues that we still see. Sometimes those young people are seen within the Paediatric Consult Liaison Service, which has child psychiatrists and paediatrics. And sometimes they're referred through to the mental health service.

Sometimes, for example, things like if a young person has, say, for example, seizures that are thought to be more psychologically based rather than physically based, they might be referred through to mental health services for a longer piece of rehabilitation work or other kinds of cognitive behavioural acceptance-type therapies.

## 8. Families with complexities

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I have grandparents of my children who come from a different generation. When we're going through this process, how can I tell them about what's going on or how can I explain to school or to friends and family about this process that my child's going through? It can be really difficult when people have different perceptions or understandings. One thing you could do is when you get the initial assessment letter, you could, for example, share that with grandparents or an aunt or uncle or people that you feel might be relevant if you think that information would be helpful for them to read. You could ask the case manager to maybe give you some written information that you could share.

They may well have given you that if they've made a diagnosis, like some basic information about the kind of condition that they've diagnosed or the medication that they've suggested. It could be if other people, like grandparents, are really key in the young person's life. It may be really helpful for them to maybe even come in and talk about their questions and about their grandchild and ways that they can help and ways that they can support you as a parent. It can be really helpful because sometimes people inadvertently undermine what you're trying to do. So that can be really helpful. If my husband and I disagree about whether our child should be medicated or, in fact, we're co-parenting and not living together, what happens when the assessment is being challenged by one of the parents?

That can be a really tricky situation because, obviously, both parents have guardianship rights and, particularly, if a child is living between two family homes. So what often happens is, obviously you would get the assessment and we would want to meet with both parents as part of the whole assessment process. If one parent is absolutely opposed to the, for example, medication, that can be really tricky. If the child is primarily living with one person, then they may go ahead and choose to give it. If it's between two families, then it's probably not a good idea to try and do that, because, obviously, there's going to be too many disputes about it and it might be given in one situation and not in another.

So if the conflict is quite significant and maybe that we can't treat with medication, or if people feel really strongly about it, one parent can go to court, one or other parent can go to court. That's very rare. It hardly ever happens. But I would have to say that sometimes we haven't been able to give medication because one parent has strongly opposed it. Would the service advocate to educate the parent who's reluctant about the benefits of it? Yes, we do make quite an effort to do that. So sometimes people don't want to come near CAF, but we will make an effort to reach out and ring the parent, invite them in by letter, send them information, all of that kind of thing.

Because, obviously, we have agreed with you that your child needs medication. We think that they will really benefit from it. We obviously will want to try and remove any barriers that there are, if we can.

## 9. Confidentiality

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And what if a parent who is 24-7 carer of a child, and they have very seldom access to another parent, what's the deal with confidentiality and whether or not it has to be shared with all of the guardians of the child? So under law, any guardian of a child has right to basic health information. So they have right to information like that the child is coming to be seen at the service, that they've been diagnosed with ADHD or whatever the diagnosis is, and that they've been treated with medication. But that would be about where it would sit, and are they doing reasonably well, or are we concerned, that kind of thing.

But all of that other more fine-grained information or confidential information, no, we wouldn't share. And if, for example... If, for example, one parent requested the notes, we have a process where we would have to go and remove any information that's relevant to

the other parent. So you have to be quite careful around the confidentiality. So you guys have systems in place to manage this. And what about the... How does confidentiality work with the young person themselves? Yeah. So... Obviously, you want the young person to be confident to share with the case manager. So depending on the age of the child, because that varies, if a child is over 16, they have the ability to kind of have a lot of health care relatively independently.

But we would always tell them up front that confidentiality has limits. And the limits are... If we're really worried about their safety, or if we're really worried they're going to hurt someone else, then it is our responsibility to alert their parents or anybody else that is relevant, you know, that could help assist in this situation, or who might potentially be at risk in this situation. So they're the kind of limits of confidentiality. And if, as a parent, I'm concerned what my child's going to reveal at a session, and I want to know what they said, can I be told? Can I find out? If a child...

Well, basically, we encourage the young people to share as much as possible, and for us to share as much as possible with parents. So we would talk with the young person about what we're going to tell the parents, and as much as possible, we get them to be as open as possible. But if there was something that they shared, and it wasn't a major risk or safety issue, and they didn't want the parents to know, then we probably wouldn't tell the parents. No, we wouldn't tell the parents. We might work with the young person to, if we thought it was something that was helpful for the parents to know, we'd work with them to try and get them to a point where they could share it.