

Advocating for yourself or on behalf of someone else can be tedious and exhausting. It can also be very frustrating if you feel unheard or dismissed. If you have questions or concerns about the care you are receiving, it is best to first speak about it with the person who cared for you or that person's supervisor or manager. If you are unsatisfied, you can contact the [Patient Care Quality Office](#).

If you continue to face an ongoing issue, you may wish to file an official complaint. Most organizations will have a public-facing official complaints process available on their website. If you are advocating for someone, describe how the issue is affecting them, but also try to understand the issue from the perspective of the organization.

Tips for filing a complaint

- Determine whether there is a formal process in place and follow the appropriate steps.
- Prepare. Make sure you understand the whole situation. If you intend on calling, prepare your questions and the key points you wish to raise to ensure effective communication.
- Learn who has the power to change the situation. A supervisor? The care home manager?
- Humanize the concern and avoid blaming any individual. Whether you are calling in or emailing, make sure the person you are talking to understands the effects of the situation on the person living with dementia and their care partners.
- Remember to avoid arguing but be persistent. It can be helpful to practise what you need to say aloud before writing a first draft of an email or letter. You could also ask someone to look over your email before sending it to remember all details and stay solutions focused.
- Include a timeline of key events to help your audience understand your concerns. You may also include any efforts you have made to resolve your concerns, including identifying who you spoke with, the date and what you discussed.
- Manage your expectations and be willing to compromise. When there are a lot of problems, decide what is most important. Remember, change takes time! Focusing on one issue can make it easier to get results.
- Follow up if you have not received a response within the expected time frame.

If filing a complaint has not been successful or is not an available option to you, you may consider writing a letter to outline the issue. The structure of an effective advocacy letter is as follows:

1. Explain who you are and why you are writing the letter.
2. Briefly explain the background of the situation, why it is a problem and what effect it is having on you or the person you're caring for.
3. Suggest a practical next step towards solving the problem.
4. Set a reasonable time frame for action and follow up if you have not received a response.
5. Copy the letter to appropriate people or agencies who can assist and keep a copy of your letter and any reply you get.

Sample letter

[Date]

[Your name]

[Your address]

[City,] B.C.

[Postal code]

CC to: Alzheimer Society of B.C., [organization's governing body, for example, a non-profit's board of directors], [primary care provider], [case manager], [local health authority]

Dear [name]:

On [date], you told me that I may no longer come to the Sunny Haven Care Home to visit my husband, Mr. Fred Citizen, who has lived there for the past two years. I know that three months ago the nursing staff began expressing concerns because my husband sometimes becomes agitated during my visits, but this is likely because Fred is lonely and confused, and he becomes upset when he sees me leaving without him. Last month I asked staff members if we could discuss strategies to manage his responsive behaviour, but I haven't been able to speak with them.

I have been a frequent visitor to Sunny Haven over the last two years, coming every day and helping my husband eat lunch and dinner. I have often mentioned matters of concern to the nursing staff, such as the condition of his toenails, his missing dentures and the need to remind him frequently to drink water so he does not become dehydrated. I realize that the staff thinks I am a nuisance, but I am not trying to be difficult; I simply want my husband to receive the best care possible. We have been married for almost 50 years and your decision to end my visits is a terrible hardship for both of us. I insist that you reconsider.

I would like to have a meeting with you within the next two weeks to resolve this issue. I would like to bring my daughter, the Home and Community Care case manager, Fred's physician [include doctor's name] and a friend who is assisting me, so that we can agree on a care plan for Fred that will include my visits. I appreciate anything you can do to help us find a mutually-acceptable solution.

Sincerely,

[Your name]

[Phone number and email]

A benefit of writing a letter is that it can be sent to multiple recipients to raise awareness of the issue.

Before you submit your letter, make sure to check for:

Tone of voice: Ensure the letter has a polite approach.

Language: Avoid inflammatory language and don't assume who is responsible.

Privacy: Seek consent from the person you're advocating for before sharing identifying information, such as their name or place of work.

Details: Describe your situation as well as your expectations for the outcome in a clear and concise manner.