

## 'I can see the characters': How reading aloud to patients can break through 'cancer fog'

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Author Neil Gaiman said, "Escapist fiction is just that: fiction that opens a door, shows the sunlight outside."



If you were going through <u>cancer treatment</u>, wouldn't you want to escape your reality for a while? Reading a story can offer an alternate world, a chance to catch your breath from the cycle of appointments and treatment, offering imagined companions. Solace is an intangible bedfellow, but a good story weaves a certain kind of magic.

However, a problem arises in the form of "cancer fog," a frequent but unwelcome side-effect of cancer and its forms of treatment. Cancer fog, also known as <u>cancer-related cognitive impairment</u>, can affect problem-solving, concentration, memory, motivation, navigation, keeping track of conversations, visual processing and hence, reading.

Reading to oneself can become frustrating for those receiving cancer treatment, so it's often abandoned. This means the therapeutic benefits of reading are denied at a time when they could be especially useful.

I previously worked in small public libraries in central Victoria and knew my community well—so well in fact, that I noticed a pattern of regular readers struggling with their reading, then abandoning it, in response to cancer treatment.

This pattern and how to address it has not been studied before, so I began to develop and evaluate a read-aloud program for people with cancer as part of my Ph.D. During the trial of this program, people affected by cancer were read to, using material chosen especially for them, by an experienced reader. Mostly, short stories were read, although some narrative non-fiction and poetry was included, alongside humorous tales and vignettes.

No expectations were placed on the participant: they did not have to operate the technology required to listen to <u>audio books</u>, they did not have to travel anywhere (the reader came to their home or local library, or they met over Zoom), they did not have to chat about the stories



(although almost all participants chose to), they did not even have to make <u>small talk</u> as the stories provided the structure and focus for the sessions.

These sessions were 45 minutes to an hour long, weekly, for six weeks. I measured well-being at the start and end of the program, and participants and <u>family members</u> were interviewed following the final session. All 38 participants reported enjoying the reading program. (One withdrew from the study due to difficulties managing deteriorating health.)

The works included short stories such as Far North by Alexander McCall Smith, many Maeve Binchy stories, including the funny Ten Snaps of Christmas, The Mouse by Saki, Yellow Jacket Jock by Colin Thiele and numerous short stories by Jojo Moyes, Monica McInerney, Jeffrey Archer, Lee Child and Agatha Christie, as well as chapters from James Herriot's books and Michael Caine's autobiography,

Close to 450 stories were read. All participants appreciated the personalization of the program and the individual reading sessions; reporting that it felt like they were being nurtured. Many spoke of the joy of being read to. Said one participant, "I felt like a king!" A participant who was having a particularly distressing experience, said, "It changed my whole attitude for the day."

Another told us, "It's a very nurturing feeling. It takes you to another world. It's lovely to listen to someone read [...] Really, it feels like a gift."

Participants with cancer fog did report they were able to focus on the listening even though they had struggled to read (visually) to themselves. Visualizing the story was not uncommon. One person told us, "I find, um, it's like you're in a movie because you're reading it to me, I find it more visual and descriptive in my brain. So I [...] can see the characters



and it's like I'm watching it."

Both regular readers and non-readers were encouraged to enroll in the program. A consequence of the research was reconnecting people to the joy (and escapism) they can find in reading, even those who thought it was hard or boring or irrelevant to our modern lifestyle.

## 'My last memory is of him chuckling'

I had the privilege of reading at the bedside of two terminally ill participants in their last days, making a difference to them and their loved ones.

One of my participants was suddenly admitted to hospital mid-way through the <u>program</u> and died not long after.

He had never been a regular reader but his preference had been humorous fiction and I found plenty to amuse him. My last memory is of him chuckling. One of his relatives sent me a <u>text message</u> with thanks: "I wanted to let you know how much he enjoyed your reading. It was a joy for me too."

The joy that the reading sessions brought to so many participants, the distraction from pain, illness and worries, the laughter and lightening of their loads, was also a comfort for families and a delight for the person reading too. It is so simple, but so powerful. Hopefully they'll continue to at least borrow audio books as the next best thing for relaxation and escapism in the midst of cancer fog.

Read-aloud programs offer distraction and escapism and have the potential to relieve or reduce treatment side-effects like nausea, pain, anxiety, depression and loneliness.



The promising <u>preliminary findings from my Ph.D. research</u> suggest these programs would be a valuable addition to the integrative oncology toolkit. Reading together is such a simple thing to do, but it has the potential to make a big difference to emotional well-being.

My goal is to see programs like this in cancer centers, hospices and as a part of palliative care programs and my next step is finding how best to make that happen.

If you have someone in your life who is going through <u>cancer</u>, try reading to them. You might just be surprised at what transpires as a result.

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