Inquiry into childhood rheumatic disease – Parliamentary committee inquiry

I am writing this as a paramedical professional, orthoptist, who has seen patients with Juvenile Idiopathic Arthritis (JIA) over my 31 year career. I work in a private sub-specialty/tertiary (1) referral ophthalmology practice. I perform the testing prior to the ophthalmologist seeing the patients. This involves measuring vision and testing as required.

The main point I would like to make about the patients we see, and develop a long term relationship with, is the significant impairments with which they live. If you or I suddenly had to live with these impairments we would be severely impacted. We would not be able to live the lives we live now, in the way we live them.

Typical characteristics of the patients I have seen over the years, is how incredibly adaptable and resilient they are. These are the patients that you see as children and they never complain. "Normal" children cry and carry on when you have to put drops in. These children don't. When you ask how they are they casually mention having to have a joint drained, or injected. Procedures that most adults find very painful. They may mention a "hot joint" – and point to a red, swollen joint they have just casually walked into your room with, without a limp. They may mention slightly blurry vision. However, when I scan (Ocular Coherence tomography – a test that is not funded by Medicare, and is an out of pocket cost) the back of their eye (the retina) they have marked macular swelling (macular oedema). They are just so adaptable, they are working around the problem. When you listen to these patient you could think they are perfectly fine. However, when you do your objective tests and measurements, that is not the case. When they complain of issues, you know that will be significant.

These patient have the ongoing cost and inconvenience of: medical examinations, tests, procedures, operations and ongoing medications. Medications do also entail side effects with long term outcomes. Despite all of this, the group of patients that I see in a sub-speciality ophthalmology practice, often end up with significant visual impairment.

The most distressing aspect of working with these patients is the extensive disabilities, despite the best available treatment (which has definitely extensively changed over the time I have been seeing these patients), that result from their condition. I have watched as patients have had to:

- Stop studying due to severe vision issues, including pain, and debilitating glare
- Change careers due to devastating vision loss
- Work around their disabilities including loss of night vision, loss of vision in an eye, loss of side vision
- Push on with everyday life, despite having to work twice as hard as everyone else.

And that is separate to their joint disease and other sequelae.

I think the most important aspects of care for these patients is:

- Ongoing access to the latest treatment paradigms – access to a living registry of Juvenile idiopathic arthritis, where the latest research is monitored and updated. Then alerts can go to specialists caring for these patients, and the patients themselves, when new treatments paradigms are found to give better outcomes.
- Ongoing monitoring and information for these patients as adults. They will have ongoing medical costs as adults and the need to keep informed to maximise outcomes. Perhaps a portal linked to the living registry of Juvenile idiopathic arthritis would be useful in this context. It could also be linked to other useful information.

- Medicare supplemented testing. At this point supplemented Ocular Coherence Tomography (OCT), as well as consultations and other testing.
- PBS supplemented medications (which can change very quickly, where PBS processes may be slow to respond).

I have always seen that our role in providing medical care to our Juvenile Idiopathic Arthritis patients is to maximise their outcomes, and minimise their impairments. This Parliamentary committee inquiry has a distinct role in enabling this care, which cannot be overstated.

1. Our practice, Eye Surgery Associates, is a tertiary referral ophthalmology practice. Patients may have seen a GP or other specialist, then an ophthalmologist, and are then referred to our sub-specialty ophthalmologists. Out ophthalmologists have done extra training, after they specialise in ophthalmology, often overseas, in very specific areas. For these patients they are inflammatory eye disease ophthalmologists.

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