

2020/2021

ANNUAL REPORT



2020/2021 has been an ongoing challenge for all organisations, and in particular the health space in which Arthritis ACT operates, with concerns over COVID, limitations on access of services to comply with restrictions and managing a complex organisation with an increased number of services and staff. We are grateful that a reliable and appropriate vaccine became available to the community, that Arthritis ACT was able to open services again, once people could actually receive that vaccine.

Whilst the 2020/21 financial year did not see any further lockdowns in the ACT and region, the community was certainly distressed and concerned, with many steering clear as much as possible from public spaces, limits further decreased access for people that could enter them, which affected our members and service delivery numbers. As a business we've had to constantly adapt and review, offering services online and on a one-to-one basis. Time has been taken to support distressed service users who could not always get the assistance they needed and our very valuable but concerned staff. Arthritis ACT successfully adapted program delivery to allow for as much variety through online programs that have continued for those that can't get out, however we have also made provision for those that can't join online from home.

During this financial year we also formalised our relationship ME/CFS ACT, and we now welcome all those members formally into our membership. We have had board representation on ME/CFS, and it's been wonderful to see the various areas of our organisation linking up and working together.

From a governance perspective, it has made us more strategic, honing the strategic plan and ensuring the Board is focused on the future planning rather than service delivery. As a Board our task is to work with the CEO and the members we represent to ensure this wonderful organisation remains relevant, has a pathway forward, and is viable. I believe that as we develop we are doing this more efficiently and it shows in the way we are growing to meet the needs of our community.

As always, I would like to thank Bec Davey – CEO, for her foresight and leadership so that Arthritis can continue to grow and meet the needs of the service users and members even through, what has been, a very difficult year. I also would like to take the opportunity to thank the staff for their commitment to excellence and our small band of volunteers for the work they do everyday for our community.

Thank you again to the Board for remaining of good humour throughout the year, it has been a pleasure to work with you all. It's been a good year as our various streams both at a Board level and within the staff team have come together to provide such a holistic service to our community members.

Carol Mead
Board Chair

FROM THE CEO

There was a joke going around late in 2020 that went along the lines of 'hey 2020, did you know that 'twenty twenty won'? Well in many ways that was so true wasn't it! Just when we thought all the dramas of early 2020, especially for us here in the ACT region, were going to be the worst we could imagine, along came 2021! For us in the financial year that we report on in this report, we were lucky. Lucky in that we had a slow, gentle reopening, but we did get back to almost life as normal for the majority of the financial year, We were enjoying pool sessions at full capacity (even with operational change rooms!), land based programs, and whilst we kept many things on 'Zoom', especially education, to allow as many as possible to participate but also to reduce the risk of last minute cancellations, we could still invite people into our rooms to watch these presentations when connections

This financial year we've achieved some really big things. We undertook and passed our first ever organisational accreditation process. We managed to transfer out of the ACT NDIS system and into the national accreditation system. We have applied for My Aged Care service status. We have increased the work that we do with clients in these areas which not only allows us to be more financially independent but it also allows us to work with our clients in a more wholistic manner which is wonderful for both us and our clients. We are definitely no longer a little NGO that just provides information to people, we are now a multi-dimensional allied health practice that puts into practice that advice that we still provide to the community. We now have the ability to have a real impact on individual's lives whilst at the same time helping to impact regional and national health and disability policy.

I want express a huge thank you to our staffing team including our loyal volunteers. It really has been a tough year with more challenges than we could have ever imagined, and the staff have remained steadfast, loyal to both our clients and our rapidly increasing business. Our staffing group love our clients. They care, they cry, they have sleepless nights because of the distress they share with our clients. The Canberra Region community is fortunate to have every single one of them.

Finally to our clients. You are the reason we do what we do. Every day you teach us something new. Thank you for putting your trust in us, and letting us walk beside you as you navigate your challenges in life.

Rebecca Davey

Hydrotherapy

Hydrotherapy has very much become a part of the political discourse in the ACT thanks to the work our dedicated pool users have undertaken supported by our office staff. Successive ACT Health Ministers and health bureaucratic staff have been on a huge learning curve as to the benefits of this therapy to the community. The ACT does not currently have a Chronic Pain Strategy in place, and this is unacceptable, and the Chronic Disease Strategy appears to have also expired. The lack of strategic forethought into preventative health and chronic health measures in the ACT is resulting in real impact in the ACT. Even recently, whilst hydrotherapy pools were officially able to remain open within the ACT, the reality was that the Government owned and operated hydrotherapy pool was closed because of its co-location in a hospital, and private pools were not able to remain open due to the costs of operation and limited support to keep their services open when not receiving funding for full time operation. If we had properly funded pools available to the community and located in accessible areas ie not within hospitals, this vital service which has been accepted by Government as an essential service would actually be able to keep operating at all times of the year, and despite pandemic. It really is time for Government to solve this problem once and for all, and to ensure that there is adequate facilities to meet the needs of the ACT community.

This financial year, Arthritis ACT has provided:

- 941 self lead hydrotherapy sessions to 9288 client visits.
- 183 instructor lead hydrotherapy sessions to 786 client visits
- over 1000 1:1 hydrotherapy sessions to people on the NDIS, My Aged Care and DVA as well as many who self-fund this support.

Demand for our hydrotherapy sessions has outstripped supply by 3:1 and during this financial year we have ceased advertising hydrotherapy due to our inability to maintain supply. People come to us because our hydrotherapy service is affordable. Whilst there are other private providers in the marketplace, the difference is the price point. If you need a therapy 3, 5 even 7 days a week, you cannot afford to be paying \$25-125 a session which is the pricing range in the for-profit sector. This is why it is essential that Government supports this essential service to ensure appropriate health care for the most vulnerable ACT residents.

Build a Better Me: Arthritis, Pain Support & ME/CFS ACT calls on the ACT Government to expedite the construction of a full time specialist hydrotherapy pool, and to enter into true commitments to improve access to services on the Northside. The demand for increased services on the Northside is now currently outstripping supply by 4:1 and this demand only continues to grow.



NDIS Supports

When the NDIS was first announced it was seen as a win for people living with disability, to have choice and control over their futures. It has been well documented how this has not panned out as planned. For people living with musculoskeletal disease that leads to permanent disability, to people living with long term chronic pain who have exhausted all medical interventions, to people living with long term ME/CFS who have no clear picture of a future without ME/CFS, dealing with the NDIS is a dispiriting, and often emotionally destructive process. It doesn't even seem to matter whether an individual has received supports from the NDIS or is still fighting to be accepted, it is an exhausting process of proving your disability, proving your needs for supports, proving that you are not 'routing' the system, and it never seems to end.

Build a Better Me has stepped in to assist our members to gain access to a low cost OT functional assessment to assist in gaining access to the NDIS. We work with medical teams to get the letters required to prove a person's disability. We have now also stepped in to provide support co-ordination to many of our clients as so many of the support co-ordinators out in the community do not understand the unique effect of the disability our members live with. We didn't do this because we thought we could make an income stream, we did this because people needed support. We also work with plan managers, LAC's and the NDIA itself to continuously educate staff in those areas as to the impact and ongoing decline in ability people living with arthritis, chronic pain and ME/CFS live with. We call on all levels of Government to improve the NDIS processes to make them enabling to people living with permanent disability, not this current emotionally destroying process that rewards the person who can afford to fund the best reports to allow them to gain the best funded supports.

Strength & Balance

Our program continued to supported through an AusSport initiative in conjunction with Arthritis Australia this year, after initially being funded by ACT Health Promotions for 3 years.

This program has become integral to the care we provide to the community. As the year progressed it became evident that it would no longer receive funding from AusSport which is really disappointing. This program has had amazing results not only in assisting members of our community to lower their risks of falls which leads to unplanned hospitalisation, lack of independence, and often, even an early death, but it has also increased socialisation for many of our members who are socially isolated. We need to reach a point where Government ceases to fund short term programs. If a 'pilot' program proves to be successful and has outcomes that improves community health, Government needs to make a commitment to ongoing commitment of these programs.





Allied Health Services

Build a Better Me: Arthritis, Pain Support & ME/CFS ACT provides a large range of Allied Health Services to the community. Our aim is to make access to allied health affordable. You should not be unable to gain allied health support because you cannot financially afford it, and waiting periods in the public health system are too extreme. In fact, many areas of the public health system refer clients to our services because they know they can't meet the individual's needs in a timely manner, and they know that one way or another we will find a way to provide the support that the individual requires.

None of our allied health services are funded externally. All our services are maintained through a user pays system. We often receive negative feedback from the private system that we 'don't charge enough - we put too much competition into the system'. Our response is constantly, there are plenty of people around who can afford to pay higher prices and benefit from a different service structure to that which we offer. We cannot let people live in our community who are unable to access any services due to pricing, and as such, we will do everything we can to provide our services to those who need them the most.

The services provided by Build a Better Me: Arthritis, Pain Support & ME/CFS ACT include:

Physiotherapy: We have 3 GLA:D trained physiotherapists who operate out of our Pearce and our Bruce offices. In addition, our physiotherapists provide a full range of services to people living with chronic pain, injuries, post-operative rehabilitation, and support prior to surgery.

Occupational Therapy: Our occupational therapist provides assistance with home, workplace and car modifications. Our OT has undertaken the specialised driver assessment training and can assist those requiring specialist intervention to either keep them on the road or get them on the road. Our OT is also instrumental in supporting our members with functional review to assist them to gain access to various levels of support including the DSP, NDIS and with issues around Housing.

Dietetics: Food is medicine and eating is social. Whether it is about losing weight to improve your pain and health outcomes, gaining weight to lessen your risk of osteoporosis, improving your nutritional absorption, or just understanding how to read food packaging labels, our dietitian can support you.

Exercise Physiology: Our EP's are found in nearly all our programs. You will meet them at the pools, you will see them in our gyms, in our Strength and Balance Program, our Nordic Walking, and providing education sessions. Exercise is also medicine, and these professionals are best suited to help you build exercise into your everyday life to improve your pain levels and lead to a more fulfilling lifestyle.

Art Therapy and Counselling: Art Therapy is a method of counselling through creativity. This is useful in eliciting emotional blockages but also in forming a new narrative and way forward for many clients. You do not have to be at all 'creative' to participate in Art Therapy. In addition to Art Therapy, Build a Better Me has also supported a counselling student this financial year and we also have a relationship with a no-cost to clients counsellor to support our clients.

Juvenile Arthritis

The ACT continues to be poorly serviced for children with musculoskeletal conditions and pain.

Government continues to ignore our calls for increased local resourcing. For many years Arthritis ACT have been educating the Government on both the need for specialist paediatric rheumatology services in the ACT and have even offered solutions. In the coming year Dr Kathy Tymms who has been providing paediatric services will retire, leaving an even bigger hole to services in the ACT. Last year we participated in a review of paediatric services through Health Consumers. We have seen no proactive outcomes as a result of this review. So for yet another year the majority of ACT families with children with juvenile arthritis continue to drive up and down the Highway to Sydney, sometimes every month, to receive care.

Arthritis ACT continues to assist families on an individual level however without adequate services in the ACT we will never have a 'community' who receive care here. This leads to families being even more isolated without a sense of having others around them who are living the dream as well. We had been in the planning process with Arthritis Australia to set up a family camp for families affected by Juvenile Arthritis, however due to the pandemic these plans have all had to be shelved as the Commonwealth Government is eager ensure funds are spent within a timeframe and continuing deliberations between the various states and territories and juvenile arthritis groups have lead to many ideas but no plans. Too many cooks in the kitchen so often lead to lesser outcomes for the public, and this is unfortunate. Moving forward it would be good to see everyone working together for better outcomes for our children rather than being more concerned about their own organisations and interest groups.



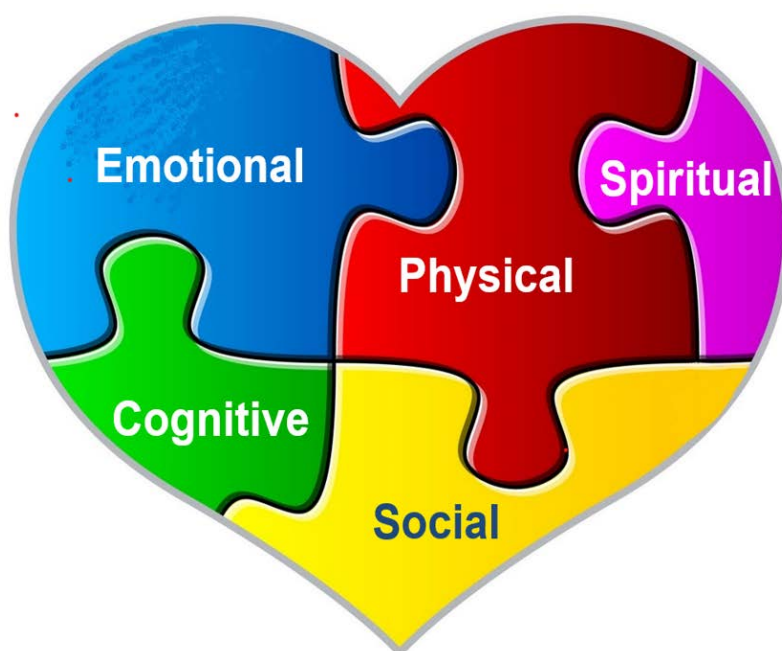
Pain Support

Pain Support has become an integral part of the Build a Better Me family this year. Supported by a reference committee and a co-opted position on the Board, the Pain Support work has become a focus of all the work undertaken at Build a Better Me. All the people that come to our organisation have a degree of pain. For some it is short term pain related to injury that we want to keep it that way - short term - but for most, it is some form of chronic pain.

People who live with chronic pain but with no absolute diagnosis are often the most overlooked people in all our community support systems. It is difficult for this group of people to gain access to the NDIS and DSP, it is often difficult for those that have had to leave the workforce to gain access to their superannuation and/or private salary insurances due to the unclear and misunderstood nature of chronic pain. It often takes a person years to get adequate supports, even to gain appropriate medical practitioner support. Chronic pain is complex, it involves the social, emotional, physical, spiritual and cognitive aspects of our lives. People become isolated, they loose relationships not just with the outside world, but often within their own families as both they and their loved ones struggle to understand what is happening.

At Build a Better Me we attempt to meet a person where they are at the point in time that we meet them. Our nurses, our allied health team, even our peer members, will rally around the individual, providing them with practical supports, a listening ear, friendship, a place to download that is safe. We also run a regular schedule of community talks to bring together not just experts in certain fields to 'teach us' what to do to get a better hold on chronic pain, but also to share experiences and opportunities. Sometimes the best supports are other people who have gone through similar experiences who can help support peers as they explore the best possible solutions for themselves.

Below is an illustration of how pain can affect the individual.



ME/CFS ACT

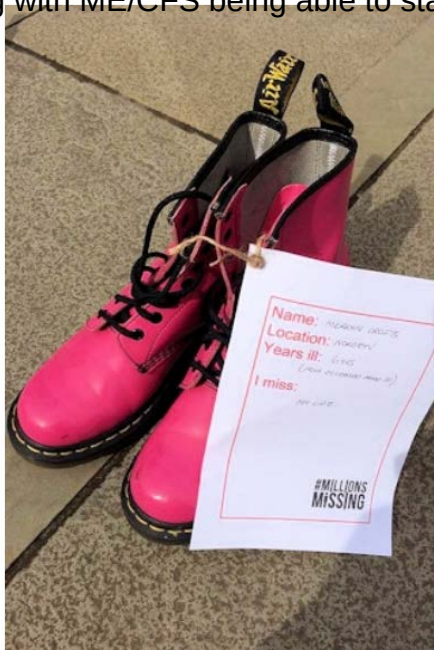
ME/CFS ACT officially united with Build a Better Me: Arthritis and Pain Support ACT in November 2020. This has been a wonderful outcome for everyone with the broader staff learning so much more about assisting those living with ME/CFS and the ME/CFS community having a much broader suite of programs they can access both because we have reduced the amount of our funding that needs to go out on straight administrative requirements and because we have a larger pool of resources we can now utilise.

This financial year we've had Mindfulness programs, a Pacing program, the ever-wonderful Self Help Course which Robyn continues to update and adapt according to the changing needs of the community and the world in which we live. We've also been able to assist many members to access the NDIS, DSP and specialty medical support.

All our programs have been available online and face to face, ensuring that those who are most disabled by ME/CFS can still have an opportunity to participate. We've also been able to have a louder voice in the media and within Government with an increased number of members coming forward for support and an increased presence in the community.

ME/CFS ACT works closely with Emerge, the Peak Body for ME/CFS in Australia, and in particular we have been working with Emerge to circulate the information around GP and Allied Health Professionals on the ThinkGP website. The beauty of this education package is registered health providers receive training points which is required for their ongoing registration for completing the program, but the program also gives a very good overview of what to expect and how to diagnose ME/CFS. It is also a really good resource for anyone in the community - you don't have to be an allied health or medical to undertake this training and it will provide anyone with a really good summary of the issues that people living with and people caring for people living with ME/CFS confront every single day.

As with Pain Support, ME/CFS has its own reference group and co-opted position on the Board as well as all financial members living with ME/CFS being able to stand for the Board.





**UNIVERSITY OF
CANBERRA**

Health Practitioner Training/Research

Build a Better Me: Arthritis, Pain Support & ME/CFS ACT have undertaken joint research projects with various universities across Australia in the areas of Rheumatology and ME/CFS during the year. In addition, we have worked with Allied Health students from the University of Canberra and UTS to provide clinical placements in OT, Exercise Physiology, Counselling, Physiotherapy and Art Therapy.

Thank You

Thank you to our Board for providing another year of oversight of this wonderful organisation.
Without you we literally cannot exist.

Carol Mead: Chair Pam Rosser: Secretary & Deputy Chair Adam Cooper: Treasurer
Hugh Watson, Margaret McCullough, Rick Lord, Libby Steeper

Thank you also to our amazing staff team who work day and night to bring the best possible services to our community.

Erica Roughton (Dietition), Rohit Bahtra (OT), Sophie Bullock (EP), Blake Dean (EP), Gwen Estigoy (EP), Natasha Perry (ES), Rhondda Bell (Art Therapist), Jacqui Couldrick (Physio), Kwong Yan Cheung (Physio), Richard Costin (Physio), Linda Spurrier (RN), Robyn Harris (ME/CFS), Natalie Bice, Grace Davey, Will Browne, Ben Dichiera, Conor Pratt, Jenette Watson, Lindy Hedgecoe, Holly Hazelwood, Anu Alahakoon, Leane Watt

Finally, thank you to all who have made donations to organisation to allow us to meet the needs of those cannot afford to pay for support and to run programs at a lower cost to allow people to attend more therapy more often. In particular a special thank you to the Shakespeare Family Trust for their donation which makes a huge difference to so many people in our organisation and to the Snow Foundation who provide one off grants to individuals who our OT identifies as needing particular equipment but the individual has no capacity to purchase this. This makes a lasting difference to the lives of so many. Thank you.

Treasurer's Report

Build a Better Me: Arthritis, Pain Support and now, since the 2020 AGM, ME/CFS ACT has continued to work hard as our community continued to be severely affected by the COVID19 Pandemic. Our organisation was in a period of growth when the pandemic hit, and as I discussed in last year's report, had finally hit the point of being self-sufficient when the pandemic hit and sent nearly all small businesses into a tailspin. We were fortunate and did receive the first tranche of Job Keeper of which some of the funds were received in this financial year, however once the second tranche was allotted, our staffing and business growth had exceeded that of the previous year, however the strict measures only looked at the growth in income, and not the growth in costs to produce that income. We are in the people business, and to increase our income we generally have to increase our staffing costs. We sell expertise and care, not widgets, and that expertise and care cannot be produced at a lesser price for higher volumes. This meant we lost a significant amount of Government funding through Job Keeper, however, as a business, we can be proud that even in the most trying of times we were meeting our base financial goals.

This financial year we have also finalised our amalgamation with ME/CFS ACT which has had a significantly better outcome for the end users of ME/CFS ACT and has allowed the retained earnings of the former Society to be transferred to the accounts of Arthritis ACT. This accounts for much of the donation level reported in the reports. It also reduces the outgoing costs of two smaller organisations as shared overheads lead to further funds being available for the community members who should benefit from both the Government and donor funds available to provide community supports and services.

It should be noted that changes to financial reporting practices have had a material affect on the outcome of the books at the end of the financial year. The change in the accounting standard means that we are now required to reflect the full value of the lease and right of use to the organisation. This means the rent reflected in the statement of profit and loss is \$67,000 greater than the prior year.

Finally, I would like to thank the regular donors to our organisation. The Shakespeare Family Trust have continued to support our community and these funds have a significant impact on the work we are able to do with people who cannot afford services. We have also been grateful recipients of a Chief Minister's Fund (Hands Across Canberra) grant to support people who need assistance with their mental health and we'd also like to recognise the assistance the Snow Foundation have made directly to many of our clients on referral from our OT to access equipment they need to improve their quality of life. Thank you too, to the support of Nexis Accountants and to our Auditors Hardwickes for their assistance throughout the year. I commend the annual financial reports to our membership.

Adam Cooper