Cardiomyopathy Australia

Has Cardiomyopathy Touched Your Life?

Supporting people with cardiomyopathy and their families.

Newsletter Number 85 — Summer 2015
Includes selected articles from Cardiomyopathy UK Newsletter

Cardiomyopathy Association of Australia Ltd is a not-for-profit registered charity
ABN 36 091 171 470
**Aims of the Association:**

- To provide the opportunity for individuals and their families to share their experiences and to support one another.
- To provide accurate and up-to-date information about Cardiomyopathy, when it is available, to members, their families and those in the medical profession.
- To increase public awareness of Cardiomyopathy.
- To foster medical research in this area.

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“The more things change, the more they remain the same.” A French editor of Le Figaro, known for his biting wit and the cultivation of dahlias, said that – in French of course. Anne was at an old people’s home, or aged care facility (different name but the same place and purpose), taking part in a concert, while David was fighting the computer over material from the UK. Anne thought as she gazed around the audience that, although she had been at Christmas concerts for old folk for years now, all somehow remained the same. She got home to an email from a friend who had lost content from his computer after an upgrade. Same things, even if different times.

One of the songs the choir sang was The White Cliffs of Dover which was a wartime favourite known to many in the audience who joined in enthusiastically, which they always do. A line in the song states firmly that “there will be peace ever after.” But there are still wars, different ones certainly, and so we must accept that although the wars may not be World War II, man is fighting man just the same in 2015 as in 1940.

We tend to think of our own corner of the world, of the places and peoples we know and understand. When Paris was so cruelly terrorized recently, we were appalled. Many letters in French and British newspapers reminded readers that many people experienced horror like that regularly in Syria, Iraq, Nigeria and Somalia and we were not similarly appalled. That is rather unfair but, like all folk, we react more to events in our backyard, both geographically and socially.

These nasty events have their counterparts in centuries gone by. Far too much of human history is blood spattered as people strive for territory, influence and power. Homes destroyed are homes destroyed whether by medieval cannon fire, a rampaging mob or the latest technical wizardry. The home owner faces the same challenges whether the destruction comes from an enemy army or a crowd of religious zealots. “The more things change, the more they remain the same.”

That is true of better aspects of mankind. Rules of hospitality are much the same the world over. Many cultures have folk tales of the rewards gained by doing the decent helpful thing. Our age is only different in the efficiency we can bring to bear on our actions. We can kill from a desktop thousands of miles away but we can also sit at a desktop and donate to a group succouring the sick and needy thousands of miles away. There is darkness but there is also bright shining light. We have much to be grateful for, not least that the West has governments that can keep their citizens safe most of the time.

Most of us will continue to keep taking the tablets, maintaining our health as much as possible, in fact, doing the same old thing. Let’s hear it for the status quo!

David and I wish you that same old thing: a Merry Christmas and a Good New Year.

Anne and David Abbott
Newsletter editors
Email: abbottdm@gil.com.au
Phone: 07 3202 8138
Dear Members and Readers

It is hard to believe another year has almost gone. I sometimes think of Anthony Newley’s “Stop the world I want to get off” as time goes by so quickly. For people with a chronic illness this may not be the case especially when recently diagnosed and they have not learnt how to deal with it.

We like to think that your Association has made a difference in learning to live with cardiomyopathy. Most of our members let us know this is the case and appreciate the regular updates of developments in diagnosis and treatment through this highly regarded newsletter. The Christmas Season is recognised as a family time and as members of the cardiomyopathy family we trust you can enjoy it and be positive about 2016.

Our thanks to members who have recently joined or renewed their membership thereby assisting your Association to support you. The modern term is “peer support” and our close association with the Heart Foundation and Chronic Illness Alliance assists us maintain best practice.

We wish to thank members who have been able to include a donation with their renewals also life members who take the opportunity at this time to do the same. As previously indicated we wish to make donated funds available for research as provided in our constitution in particular for genetic research. We expect to provide more details in the Autumn newsletter.

Donations may be made at any time by direct credit to our Donations Account at Defence Bank BSB 803 205 A/C 140266 or cheque to the address below. Donations are tax deductible.

If there are any matters you would like the National Executive to consider please contact our Secretary by email to info@cmaa.org.au or by letter to our new address at P.O. Box 43, Doncaster Heights Vic 3109.

Best wishes to you and yours for 2016

Alistair Kerr
President
On behalf of the National Executive
Hello Victoria and all members

I wish you a Merry Christmas and a happy, healthy 2016.

Our November meeting was well attended where once again Dr Andris Ellims was our guest speaker. Andris is a great supporter of CMAA who willingly responds to our requests. His presentation on HCM and genetic screening was well received then he responded to some great questions. He also spoke about research at The Alfred a topic of great interest for our members.

I am awaiting confirmation of 2016 meeting dates in March, July and November at Epworth Hospital and will post them on our website when available.

I hope to see you at our next lunch which will be at a new venue, Wheelers Hill Hotel (cnr Ferntree Gully & Jells Rd, Wheelers Hill) on Saturday 23 January 2016. I recommend you enjoy a lovely meal with views of the Dandenongs. Please RSVP by 21 January.

Please stay safe over the holiday period.

With kind regards

Joan Kerr
Victorian Contact
Tel: (03) 9848 7082
E: jakerr@iprimus.com.au

Are you able to donate some spare time?

One of the questions that is regularly asked of the Association is “how many paid staff do you employ?”. The answer of course is “zero” and has been so for the more than 20 years of the Association’s existence. We have always operated entirely with volunteers.

This sometimes comes as a surprise to people, given the level of services and activities provided. It does mean that our member subscriptions are devoted totally to the out of pocket costs of providing support services.

Like other organisations that are dependent on volunteers, we are under continued pressure to enlist the resources and skills needed to function effectively and efficiently.

We would dearly love to hear from anyone prepared to make time available to assist in the running of the Association. In the first instance, an email to info@cmaa.org.au indicating your interest would be welcome, or please contact your State Contact.
Hi from Tasmania

The Holmes family of Molesworth, in southern Tasmania, were recently the recipients of a major home renovation after it was revealed that several members were battling with Danon Disease, which I understand resembles hypertrophic cardiomyopathy, as it weakens heart and skeletal muscles. A local radio station teamed up with at least one hundred tradesmen to complete the work. Another example of a generous Tasmanian community in action.

Although it seems a long way off, I would like to draw your attention to our Annual Luncheon. In March this year we decided to look at a date in April for 2016. I will contact you all well in advance with a specific date and the full details.

It was good to catch up with our Membership Secretary Peter and his wife Cathy recently in Hobart. Keep well and please contact me with any newsletter contributions or matters of concern at vbaustin@bigpond.net.au or 6229 6181.

Brian Austin (Tasmanian Contact)

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**Member Profile**

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<tr>
<th>Q</th>
<th>A</th>
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<tbody>
<tr>
<td><strong>Name and location?</strong></td>
<td>Janny, from Bakers Beach, Tasmania</td>
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<tr>
<td><strong>What type of CM do you have?</strong></td>
<td>Dilated</td>
</tr>
<tr>
<td><strong>When was it diagnosed?</strong></td>
<td>2010</td>
</tr>
<tr>
<td><strong>What were your symptoms?</strong></td>
<td>Fluid retention, difficulty breathing</td>
</tr>
<tr>
<td><strong>What treatment was suggested?</strong></td>
<td>Medication, ICD, (Resynchronization therapy)</td>
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<td><strong>How often do you see a cardiologist?</strong></td>
<td>6 monthly reviews</td>
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<tr>
<td><strong>How does CM affect your life?</strong></td>
<td>Have learned to listen to my body with 10 minute “Nanna” naps for tiredness.</td>
</tr>
<tr>
<td><strong>How does CM impact on the lives of other family members?</strong></td>
<td>My children now have regular check-ups.</td>
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<tr>
<td><strong>Do you keep abreast of research?</strong></td>
<td>Yes, through bi-annual CM Conferences</td>
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<tr>
<td><strong>Do others in your family carry the CM gene?</strong></td>
<td>Yes, my son.</td>
</tr>
<tr>
<td><strong>Are you happy to make contact with other CM sufferers?</strong></td>
<td>Yes.</td>
</tr>
<tr>
<td><strong>Have you found CMAA to be beneficial?</strong></td>
<td>I enjoy reading the CMAA Newsletter. The feeling that you are not alone.</td>
</tr>
<tr>
<td><strong>Any other comments?</strong></td>
<td>I am very thankful for the care that I have, I am responding well to treatment and I do not allow my heart condition to define me.</td>
</tr>
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SA and NT News

Hello to all members in SA & NT

I Hope everyone is well. Another year almost over, and like every year not sure where the time has gone.

We are saddened to say that one of our Members passed away in October. Alma was a Member of CMAA for many years and came with her Husband Mike to almost every Meeting. Our thoughts are with him. She will be sadly missed.

We held a fundraising Evening on Thursday the 19th November at Totally Wrapped, a gift shop that sells all sorts of gifts and Homewares. They kindly donated 10% of the sales to CMAA. We had 22 people attend and everyone had a fun evening.

We had planned to have lunch at the Maylands Hotel, but unfortunately the date seemed to clash with Everyone, so I cancelled it and changed it to Thursday the 3rd December and that was much more successful. It was nice way to end the year.

We already have some plans in place for 2016. On February the 9th we have Dr Alistair Begg Cardiologist from SA Heart as our Guest Speaker, and Dr Richard Hillock later in the year. Hopefully this will be of interest to everyone. Details will be on the Website shortly.

I hope everyone has a Great Christmas and New Year.

Take Care
Kerry Shaddick — SA and NT  Contact:
Phone 08 8270 7747
Email kerry.shaddick@hotmail.com

Thank You

Our sincere thanks to our sponsor, Direct Response Australia (DRA) whose Sydney manager, Wendy Cosgrave and her staff have undertaken the printing, collating and distribution of printed copies of our Newsletter. Without this much appreciated assistance, our Newsletter simply would not exist in its printed form.
Hello from Queensland

Our last meeting for 2015 was held on Saturday 5 December. As usual, about a dozen or so members attended. We exchanged experiences and updated ourselves on recent developments in an informal setting over refreshments.

For 2016, our meeting dates will remain unchanged on the first Saturdays in March, June, September and December. However, with increasing interest from members and potential members in the Gold Coast region, we are looking at having 2 meetings (March and September) at the Gold Coast University Hospital and the other 2 (June and December) in Brisbane at our current venue. You will receive further details in the New Year.

You will see a separate announcement in this newsletter that the CMAA National Annual General Meeting and seminar will be held at the Gold Coast University Hospital on Saturday 3 September, which will coincide with our usual quarterly Queensland meeting. We encourage you all to note this date and venue in your diaries and organizers for 2016. It’s an ideal opportunity to meet the President and his Executive Committee and learn about some of the latest developments in managing CM from experienced practitioners. It will also be an opportunity to see a state of the art cardiac hospital facility.

The Gold Coast University hospital is accessible by public transport from various parts of the Gold Coast and is also accessible from Brisbane by regular train and bus connections. Further details will be provided closer to the date. In the meantime, if you are willing to assist in the organisation of the AGM and seminar, please let us know.

Our best wishes to you all for a safe and happy Christmas and a healthy 2016.

David and Anne Abbott
Queensland State contacts
phone: 07 3202 8138
email: abbottdm@gil.com.au

Are you happy to continue to receive invitations to our regular meetings by mail or email?

If you find you are never able to attend our meetings and events and would therefore rather not receive invitations, please let us know.

Just call your State Contact (see details on each State Contact’s report) or drop a line to

Membership Secretary
P.O. Box 43 Doncaster Heights, Victoria 3109
Young Members Group (YMG)

Miranda is continuing to make good progress after her heart transplant and thanks everyone for their good wishes. She expects to make a welcome return to representing Young Members in the New Year and resuming this feature of the newsletter. We wish her a continuing improvement in her health in 2016.

(Newsletter editors)

Miranda Hill
miranda82@ymail.com
0411 962 946

CMAA Young Members’ Group

This is an exciting and timely initiative for CMAA to pursue, harnessing the enthusiasm of Miranda and other young members to respond to their special needs and interests. We would welcome hearing first hand the issues facing younger people with CM. Please contact Miranda (details above) to express your interest in being part of the Young Members’ Group and sharing your experiences.

Have you enrolled in the National Genetic Heart Disease Registry?

If you or a family member have an inherited cardiomyopathy you may be eligible to take part in this registry. We are aiming to enroll every family with an inherited heart disease in Australia, which will assist Australian research groups learn more about these conditions.

More information, including patient information sheets can be found at our website www.registry.centenary.org.au

To get an enrolment pack please contact Dr Jodie Ingles or Laura Yeates.
Molecular Cardiology Centenary Institute
Locked Bag No 6 Newtown NSW 2042
Phone 02 9565 6185 Wednesday—Friday
Email: j.ingles@centenary.org.au
News from New South Wales

New Contact Person appointed for NSW

Good news—we have a NSW State contact again. He is Dr Stephen Ellwood, a general practitioner at Moruya, on the NSW South Coast, where he has been for the past 20 years. Steve, a member for many years, was diagnosed with CM in 2005 and had a heart transplant two years ago. He’s keen to make a contribution to Cardiomyopathy Australia and will handle phone and email enquiries. Steve’s contacts are mobile: 0438 206 268 (outside office hours or by text message) and email: stevan.ellwood@bigpond.com

I’m sure you’ll all be pleased with this news. Joan Kerr in Victoria has done a marvellous job acting as NSW contact over the past three years—a big ask and a big thank you, Joan. The website and the phone message bank will be updated for the change.

We still need someone to organise information meetings in Sydney, as Steve is too far away. Now that the work has been split in this way, we are hopeful that someone will volunteer to take on the role of meeting organiser. If you would like more information on the role, please do not hesitate to contact the Association’s Secretary, Janet George, at info@cmaa.org.au.

Lunch Meetings

All members (including any visiting Sydney) and their family and friends are welcome at the informal lunches held on the last Friday of every month at the Second Floor Bistro, Mosman RSL Club, Military Road, Mosman, NSW. Please make a note in your diaries and organisers.

We meet at 12.00 noon for a 12.30 pm start. Please RSVP your intention to attend to info@cmaa.org.au.

We have a new postal address

Please note that Cardiomyopathy Australia now has a new postal address:

PO Box 43, Doncaster Heights, VIC, 3109

Please amend your records accordingly—thank you

A new edition of Margot Maurice's book, 'Six Months to Live', is now available as a print book (physical book) due to the demand from those members who prefer this format. This new edition is published by Amazon books worldwide www.amazon.com.au or can be ordered from your favourite bookseller. Orders can be made online and delivered to your home within the week.

A sequel to Six Months to Live will be available as both a print and Ebook in the first half of 2016. It is called 'The Eleventh Hour.'

A percentage of profits will be paid to Cardiomyopathy Australia.
News from ACT

Hello from Canberra & regions,
At last we have warm days & a relief from cold weather.
Apologies for being out of action with the newsletters of late. Life goes on in all of its forms & I am now back on deck.
We have not had any meetings this year so if you could contact me this would be great. If any people are interested in a catch up lunch early next year please contact me so I can organise it.
If you know of any younger people who have Cardiomyopathy please let me know. Please also remember that the Association has a Young Members’ Group (see p9).
Can you please consider writing about your experience with Cardiomyopathy for inclusion in our newsletter. This is a simple way of helping others by sharing experiences.
I wish you all a great Christmas, plus a New Year for 2016 & may good things come your way.

Thank you
Judy Hunter Quinn—Contact ACT
judyhq@bigpond.com
Mb: 0412 900 878
please use this mobile phone number rather than the landline number previously provided as a contact

News from Western Australia

G’day from WA, it's been such a busy, busy year for me & I find it difficult to keep up & am slowing down since my op 6 years ago.
There isn't a lot if news to write about from 2015. Please feel free to call me anytime if you need.

May everyone have a very Merry Christmas, Happy New Year & the festive season & summer be safe & enjoyable.

Cheers, Rhonda

Rhonda Jobson, WA State Contact—phone (08) 9319 1034

2016 AGM and Seminar—Date and Venue

The 2016 AGM and Seminar is to be held on Saturday 3 September, 2016 at the Gold Coast University Hospital.
Further details will be included in the Autumn newsletter and posted on the cmaa website.
Health Literacy, Good Health and Wellbeing

‘Health literacy’ has been a buzz-word in health policy circles for some years now. The World Health Organization’s health promotion policies of 2009, the Australian Government’s National Statement on Health Literacy released in 2014 and various recent policy statements of State governments have drawn attention to the need for health professionals and patients to understand the importance of health literacy and develop skills in its use.

Put simply, health literacy refers to the knowledge and skills people should have to be able to access, understand and use information necessary for good health. This may be at the individual level, or at the levels of communities, consumer organisations and the health professions. Understanding what we need to know for our health may seem obvious, but it is a complex matter. It has been estimated that 60 per cent of the Australian population has a low level of health literacy (ABS 2006). That percentage reflects differences in, for example, age, education, ethnicity, place of residence.

Why is health literacy important? Since colonial days, doctors’ knowledge and skills have increased, along with advances in drug treatments and technical devices. In earlier years, people generally relied on their doctors’ advice unquestioningly. More recently, with the availability of websites and social media, people have looked for information from other sources and some of these are of questionable reliability. It is therefore important to access information from reliable sources, to learn to evaluate that information and then to put it into practice. Doing so helps people achieve greater responsibility for their health, with the likelihood of earlier treatment, and at the same time it is likely to reduce public expenditure on treatment of avoidable illnesses.

So how to develop health literacy? The challenge is not only for patients and carers, but for health professionals and policy-makers as well. For patients and carers, with respect to cardiomyopathy, this includes such areas as:

1. Understanding rights and duties: A first step to understand our rights and duties in the health system is understanding that everyone is entitled to information about their illness and its treatment, including risks and benefits. It is the duty of the health professional to provide that information and obtain consent to treatment. The other side of a right is a duty: in this case we as patients have a duty to comply with the treatment to which we have agreed.

   Strategies:
   - Ensure you are well prepared for your visit to the doctor or other health professional, including questions as to the benefits and risks of suggested treatments.
   - For some procedures such as surgery written consent is required. It is also needed if you are invited to take part in research, such as a clinical trial of a new treatment. If unsure about agreeing you should ask for further explanation.
   - When you have agreed to treatment, such as medicines, you must take them as directed, knowing you may ask the doctor if you experience any unexpected effects. As well, you should make sure you attend scheduled appointments.

2. Visiting the doctor: It is important to prepare for your visit, which requires being clear about why you are there; expressing as clearly as possible the symptoms you are experiencing; answering the doctor’s questions as fully as possible; asking about what happens now and into the future.

   Strategies:
   - Make a list of your symptoms and the questions you have beforehand;
   - take a family member or friend with you to the consultation;
   - listen carefully and be sure you understand what the doctor is saying – even if it means asking for it to be repeated!
   - Take notes if you need to aid your memory in what may be a stressful situation.

(continued)
Health Literacy, Good Health and Wellbeing (continued)

3. **Diagnosis and treatment:** This may involve further tests, medication, perhaps implantation of a device, and may include a cardiac rehabilitation program.

   **Strategies:**
   - Learn as much as you can about your condition, primarily from your treating doctors and other health professionals; read about it from reliable sources. These include the links to other organisations on the Cardiomyopathy Association’s website at [www.cmaa.org.au](http://www.cmaa.org.au), including the information on cardiomyopathy on the Heart Foundation website at [www.heartfoundation.org.au/you and your heart/cardiovascular conditions/cardiomyopathy](http://www.heartfoundation.org.au/you and your heart/cardiovascular conditions/cardiomyopathy).
   - Your pharmacist is knowledgeable about medicines and able to answer your questions. Be aware that there is a ‘safety net’ for frequent users of prescribed medicines and to access that you will require the pharmacist’s record of your usage. Details of the scheme are at [www.pbs.gov.au/info](http://www.pbs.gov.au/info).
   - Comply with the instructions for using your medication and other instructions from your doctors/health professionals for daily living, eg exercise, alcohol use and dietary matters.
   - Asking your GP to develop a care plan is a useful way to develop health goals and to make you eligible for Medicare rebates for allied health professional consultations, eg dietitian or exercise physiologist.
   - Keep your GP in the loop about how you are feeling – as practitioners in the front line, they are well-placed to be aware of the medical and psychological aspects of your wellbeing.
   - If you are unhappy with your treating health professionals, then it is OK to ask your GP for a referral to another practitioner. It is important that your specialist has expertise in cardiomyopathy as an area of cardiology and in its up-to-date treatments.
   - If you are concerned that there may be a family history of cardiomyopathy, or a genetic link is indicated, the National Genetic Heart Disease Registry at [www.heartregistry.org.au](http://www.heartregistry.org.au) is a first point of contact for the opportunity to speak with one of their genetic counsellors.

4. **In the longer term:** Given the improvements in medicines and technical devices such as ICDs, people may live with cardiomyopathy for many years, depending on the severity of their condition at time of diagnosis.

   **Strategies:** Some people find becoming health literate about their cardiomyopathy through reading is enough. This should include reading the articles in the Cardiomyopathy Association Newsletter, and sending unanswered questions to the ‘Dear Doctor’ column, to be answered by our medical advisers. People often find that having someone to talk to who understands is very helpful. Health literacy in that case may be enhanced by:
   - Keeping talking with your GP. They are best placed to help work out your questions and help you get answers
   - taking part in Cardiomyopathy Association activities, be that directly by attending meetings, information sessions or informal get-togethers, contributing to the newsletter, becoming involved in the Phonelink, especially if living outside the urban area. There are always opportunities to become involved in State Contact and National Executive roles.

(continued)
Health Literacy, Good Health and Wellbeing (continued)

5. **For people with low literacy or English language skills:** Health professionals are increasingly being trained to improve their communication skills in working with people of Culturally and Linguistically Different (CALD) or Aboriginal and Torres Strait Islander (ATSI) backgrounds. Some community organisations, including those specific to certain ethnic groups, also provide information and may have specialised staff, such as social workers, to help negotiate what is a complex system of health services and of knowledge.

- For people with CALD background, most government health services provide interpreter services.
- When making an appointment, ask if an interpreter service can be arranged.
- Check out whether there is a community organisation of your ethnicity with a social work service available.

The importance of health literacy can’t be overstated. Understanding our health and illness is a first step to improving and maintaining our good health, including its psychological, social and spiritual dimensions.

Hopefully, the information above will help us towards knowledge and action, as well as towards an increased level of responsibility for our own good health and wellbeing.

*Janet George*

*(Dr Kate George and Alistair Kerr are thanked for their helpful comments on a draft of this article)*

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Do you have a story to tell?

*There’s nothing like sharing actual experiences with people in similar situations who are having to address common issues. Members’ stories always have great appeal with our readers. If you would like to share your story with your fellow members, please contact your newsletter editors (see page 3) or State Contact Person. Please remember that we are available to help with the writing of articles.*

*Anne and David Abbott—Newsletter editors*
Dear Doctor........

Question:
I was diagnosed with hypertrophic cardiomyopathy around 20 years ago. I recently needed surgery under general anaesthetic for a non-cardiac condition and the anaesthetist explained the importance of getting the level of anaesthetic just right for patients with cardiac conditions such as HCM. Apparently, too little may adversely affect the surgical procedure, however, too much may adversely affect the heart’s operations. While I have always been advised to disclose my HCM condition before undergoing any procedures involving anaesthetic, including dentistry, I was not aware of the fine tolerance limits that may need to be observed.

Are there non-cardiac surgical procedures, such as hip and knee replacements that present major risks for people with CM? and are there any risks for them during the post surgery recovery process, particularly from residual anaesthetic?

Answer:
The main problem with general anaesthetics for patients with hypertrophic cardiomyopathy is fluctuation in blood pressure during surgery. This can be caused by the anaesthetic drugs but also by fluid shifts and blood loss during the operation. If an operation is performed under an epidural anaesthetic this also may affect blood pressure. Of the hypertrophic cardiomyopathy patients those with outflow tract obstruction (obstructive) are more likely to be sensitive to this.

Therefore it is a fine line between dropping blood pressure and maintaining it and also keeping adequate fluids up to the patient. There is no particular problem during recovery apart from the usual care. Patients with hypertrophic cardiomyopathy may be more prone to tachycardias (fast heart rates) around the time of surgery which is watched for.

Almost all patients with HCM and in fact any cardiomyopathy can safely undergo anaesthetic as long as the anaesthetist, surgeon and all concerned are aware of their heart condition and take appropriate steps to monitor their status.

If there is something on your mind that you’d like an answer on, please either email your Dear Doctor questions to Newsletter on our website (www.cmaa.org.au) or post them to CMAA Ltd, PO Box 43, Doncaster Heights, VIC 3109 for inclusion in future issues.
Recent Research Studies

Causes of arrhythmogenic ventricular cardiomyopathy (AVC)

Dr Jeffrey Tobin and his team at Cincinnati Children’s Hospital have been investigating the effects of endurance exercise on this condition. They have started to find some possibly helpful leads to further research after working with mice that mimic the condition in humans. AVC is a genetic condition that affects the structure of the heart wall. It is the most common cause of sudden cardiac death during intense exercise, and is commonly undetected until then. It is very difficult to detect and diagnose.

Dr Tobin’s team have found a way of detecting early signs of trouble in the heart’s wall before cardiac symptoms are present. Cells in the heart are held together by proteins called desmosomes. Faults in these proteins can make the links between the cells give way. The gaps get filled by fatty tissue. These gaps are not easily picked up by the tools available at present to cardiologists. Dr Tobin and his team have found a biological marker present in the early stages of AVC which might well be a new approach to earlier detection.

The marker is – wait for it! – the Wnt-beta-catenin pathway which has something to do with promoting the growth of new cells and preventing fat deposits. It may well be involved in stopping those gaps in the heart wall being filled by fatty deposits. Dr Tobin’s team have measured changes in that pathway during physical exercise in their laboratory mice suffering from AVC. More research is needed but this result may turn out to be a very promising lead.

Do remember that much research follows hopeful leads that take the scientists nowhere and they have to return to the beginning. It’s rather like a game of snakes and ladders; you may be going great guns but land on the snake at 99 and slither nearly back to the start. We must be grateful for the amount of research that does lead to breakthroughs.

This research is published in the American Journal of Physiology - Heart and Circulatory Physiology.

Our mind and attitude affects so much - so join CMAA!

Holger Cramer and colleagues have published in Deutsches Arzteblatt International their conclusions following a review and analysis of published material. Mind-body medicine which is a holistic approach can help to ward off more heart attacks than conventional medicine alone.

Patients remain on a drug regime but benefit from having their fears and questions addressed, their general circumstances improved, their knowledge about their condition increased and their family involved so that they can deal with their situation better and look forward.

It is pleasant to have professionals acknowledge the value of self-help groups. So many times patients tell us that meeting fellow patients face-to-face and talking with them has helped enormously. Patients are individuals first and then patients. Attitude colours how we react and CMAA can help with adjusting attitude in folk reeling from that initial diagnosis.

Transcendental meditation helps to relax the mind and body. Closing the eyes, sitting comfortably for 20 minutes twice a day and emptying our mind by concentrating on relaxing has been shown to stimulate the production of telomerase, an enzyme linked with reduced blood pressure and mortality. (from the journal PLOS One) The most difficult thing here is learning to relax but persevere. It is worthwhile.
We are what we eat and drink!

How to incorporate more superfoods into your diet

These foods can be incorporated into a healthy diet when available, but do not go breaking the bank or searching the globe trying to find them. The secret is that any leafy green vegetable or berry commonly found in your grocery store will provide many of the same benefits found in the premium priced superfoods.

Buy your produce in season and from local sources to ensure the highest nutrient content. Do not discount your ordinary apple or carrot either; all fruits and vegetables should be referred to as superfoods! Keep in mind that the more processed foods you can replace with whole foods like fruits or vegetables, the healthier you will be.

Quick tips:
- Eat the rainbow! Look at the colours on your plate. Is all of your food brown or beige? Then it is likely that antioxidant levels are low. Add in foods with rich color like kale, beets and berries
- Add shredded greens to soups and stir fries
- Try replacing your beef or poultry with salmon or tofu
- Add berries to oatmeal, cereal, salads or baked goods
- Make sure you have a fruit or a vegetable every time you eat, meals and snacks included
- Have a daily green or herbal tea
- Spice it up! Make turmeric, cumin, oregano, ginger, clove and cinnamon your go-to spices to ramp up the antioxidant content of your meals
- Snack on nuts, seeds (especially Brazil nuts and sunflower seeds) and dried fruit (with no sugar or salt added).

(sourced from Megan Ware, Medical News Today, December 2015)

Energy drinks and blood pressure

In a new study published in the Journal of American Medical Association, researchers found that a single can of energy drink increased blood pressure and stress hormone responses among young adults.

Dr. Anna Svatickova, a cardiology fellow at Mayo Clinic in Rochester, MN, and colleagues found that young adults who consumed one 16-ounce energy drink showed a rise in blood pressure and an increase in stress hormone responses within 30 minutes, which may raise cardiovascular risk.

The team presented their findings at the American Heart Association's Scientific Sessions 2015.

Energy drinks - marketed as beverages that can boost physical and mental performance - are growing in popularity, particularly among adolescents and young adults in the US. According to the Centers for Disease Control and Prevention, energy drinks are regularly consumed by around 31% of teenagers aged 12-17 and 34% of adults aged 18-24.

But with the rise in energy drink consumption comes an increase in public health concern; the beverages have been linked to a number of severe side effects. A study reported by Medical News Today in 2013, for example, linked energy drinks to altered heart function.

What is more, a 2013 report from the Substance Abuse and Mental Health Services Administration found the number of emergency department visits in the US involving energy drink consumption more than doubled between 2007-11, from 10,068 visits to 20,783.

Caffeine is believed to be the most harmful ingredient in energy drinks; a single can or bottle contains anything from around 80 mg of caffeine to more than 500 mg. For comparison, a 500 mg cup of coffee contains an average of 100 mg of caffeine. Energy drinks also have a high sugar content and may contain other plant-based stimulants that produce side effects comparable to those of caffeine.

More evidence is available on the important role played by our intestinal bacteria not only on the health of our bodies but in influencing our mind and mood changes. We'll leave you to do your own research on this topic!

(newsletter editors)
Banana and strawberry breakfast smoothie
An easy and healthy summer refreshment

Serves 2
Preparation time: 5 minutes
Cooking time: nil

Ingredients:
- 1/2 small banana
- 1/2 cup chopped fresh strawberries
- 3/4 cup reduced fat milk
- 1/4 cup reduced fat natural yoghurt
- 1 tablespoon honey
- 1 teaspoon wheat germ
- 1/4 cup crushed ice

Look for products with the Heart Foundation Tick.
The Tick highlights healthier choices when comparing products.
Remember all fresh fruit and vegetables automatically qualify for the Tick.

Instructions:
1. Place the fruit into a blender with the milk, yoghurt, honey, wheat germ and ice. Blend until smooth and serve immediately in a chilled glass.

If you enjoyed this, you may like to try these other smoothies on the Heart Foundation recipe website:
- Mixed berry smoothie
- Mango and passionfruit smoothie

Recipe and image reproduced with permission. © 2015 National Heart Foundation of Australia.
For other healthier recipe ideas, visit www.heartfoundation.org.au/recipes or phone 1300 36 27 87.
The articles in this section of the Newsletter are excerpts from the Cardiomyopathy UK magazine. Reproduction of the excerpts is possible with the kind permission of Cardiomyopathy UK for which we express our appreciation. Cardiomyopathy UK wishes to acknowledge the continuing support of the British Heart Foundation.

Richard tells doctors about the impact of heart failure

Support volunteer Richard Mindham has been telling doctors, nurses, researchers and patients about the psychological impact of heart failure.

Richard, who has dilated cardiomyopathy, was addressing a heart failure event at the Royal Society of Medicine in London.

The conference was part of a programme to update doctors and give patients and carers a chance to tell the medical profession about the impact that diagnosis and treatment can have.

Organisers say healthcare professionals learn from and are inspired to improve care by hearing from patients.

The event was supported by the BHF and Cardiomyopathy UK sponsored a stand there.

Richard said that when he was diagnosed with cardiomyopathy the only psychological support he had was from Cardiomyopathy UK. It had taken him about five years to fully come to terms with the diagnosis and the changes he had to make to his life.

Richard has been a support volunteer for Cardiomyopathy UK for many years. In that role he talks to others affected by cardiomyopathy by telephone and email.

How the heart beats

We are planning to include a series of articles in My Life on the various heart rhythm problems (arrhythmias) that can occur with cardiomyopathy.

As a starting point we thought a brief article describing how the heart beats.

Every day it will beat approximately 100,000 times at rest and pump around 7,500 litres (2,000 gallons) of blood. This is coordinated by the transmission of small electrical impulses which are generated in and transmitted through channels in the heart.

The heart’s function is to pump blood around the body. It is fundamentally made up of two types of cells: muscle cells which provide the contraction of the heart necessary to pump the blood, and electrical cells which generate the electrical impulses required to cause the contraction at the right time.

An electrical impulse is produced in an area in the right atrium called the sinus node. This impulse spreads across the left and right atrium and collects at the atrio-ventricular node, a point at the junction between the atria and the ventricles.

The impulse is then transmitted down to the ventricle via channels known as bundles. There is a left and right bundle and some of you may have heard the term ‘bundle branch block’ which is used when, for some reason, an impulse is unable to travel down one of these bundles.

The electrical impulse spreads across the ventricles causing them to contract. The heart then prepares for the next impulse. This is a process which happens every time the heart beats. These electrical impulses can be recorded on an electrocardiogram (ECG) and provide a wealth of information on the heart’s function.

If you want to know more about cardiomyopathy, ask for one of our cardiomyopathy booklets, produced with support from the British Heart Foundation.

We have booklets about each of the main types of cardiomyopathy — dilated, hypertrophic and arrhythmogenic right ventricular cardiomyopathy.

Information about other types of cardiomyopathy is on our website, cardiomypathy.org We also have a booklet about living with cardiomyopathy.
Hypertrophic cardiomyopathy (HCM) is a common, inherited disease of the heart muscle and causes abnormal thickening of the main pumping chamber of the heart, the left ventricle. Patients with HCM have a higher risk of stroke than the general population and this article reviews stroke and its prevention.

**Stroke in HCM**

Most patients with HCM have a good life expectancy but unfortunately some are affected by stroke (cerebrovascular accident), a serious neurological disorder caused by the sudden interruption of the blood supply to the brain. Brain tissue is starved of blood and the ensuing damage can cause sudden limb weakness, visual loss or difficulty speaking.

In HCM, stroke can be caused by blood clots from the heart that dislodge, travel to the brain and obstruct blood vessels. Stroke refers to permanent neurological damage; if the neurological deficit lasts less than 24 hours, the term mini-stroke (transient ischaemic attack) is used.

Occasionally, clots from the heart can block off the blood vessels to the legs, arms, eye or kidneys which result in local tissue damage. This process is called peripheral embolisation and is essentially a variant of stroke. In some patients, strokes are caused by narrowing of the blood vessels, most commonly in the neck or brain or less commonly by bleeding in the brain.

Approximately 4% of patients with HCM are affected by stroke over the course of ten years. If diagnosed early, stroke can be treated with a clot-busting drug that restores the blood flow and limits brain damage. After stroke, rehabilitation is essential to restore lost function. Despite advances in drug treatment and rehabilitation, stroke remains a devastating illness and a significant number of patients are disabled or die as a direct consequence. It is therefore of utmost importance to prevent strokes rather than to deal with the consequences.

**Stroke prevention**

Most strokes in HCM are thought to be caused by blood clots, most likely formed as a consequence of stagnant blood in the heart. Sluggish blood flow is encountered in atrial fibrillation (AF), an abnormal heart rhythm characterised by an irregular heartbeat. Approximately a fifth of HCM patients develop AF over the course of ten years. If AF is detected and this approach is effective in preventing a significant number of strokes. However, a substantial number of strokes occur in patients without AF and this is a major limitation. Identifying HCM patients without AF who are at risk of stroke and would benefit from blood thinning is very important.

**A new risk prediction model for stroke: HCM Risk-CVA**

To improve the prevention of stroke in HCM, a collaboration of European investigators developed a new method of assessing risk called "HCM Risk-CVA". This model provides a numerical estimate of risk of stroke in patients with and without AF. This is achieved using a mathematical formula based on data from a large group of HCM patients.

HCM Risk-CVA works similar to health insurance policies where companies use data from previous customers to calculate the risk associated with a particular applicant. In the same way that a middle-aged applicant with a long list of medical problems pays a higher premium than a young applicant without a medical history, an older HCM patient with palpitations and additional risk factors has a higher risk of stroke than a younger patient without any risk factors.

**Assessing the risk of CVA using HCM Risk-CVA**

The aim of HCM Risk-CVA is to identify patients at high risk of stroke who would benefit from more frequent follow up and early blood thinning. The risk assessment should include a clinical review, an ultrasound scan of the heart (echocardiogram) and a heart rhythm monitor (Holter).

In addition to AF, the following factors have been found to be associated with a high risk of future stroke:

- Age of the patient: the older the patient the higher the risk of stroke
- History of a previous stroke
- A New York Heart Association class (NYHA class): a classification for shortness of breath
- Enlarged left atrium
- History of vascular disease
- Severity of thickening of the left ventricle

Patients with these risk factors should be followed up more closely, with frequent heart rhythm monitoring and institution of blood thinning treatment at the earliest sign of atrial fibrillation or in some cases prior to the development of atrial fibrillation.

**Conclusions and future directions**

Predicting the risk of a stroke, irrespective of method or heart condition, is challenging. HCM Risk-CVA represents an improvement in the management of HCM patients, but it is not perfect and currently it is not possible to predict all cases of stroke. This new tool allows clinicians to target high risk patients for closer monitoring and early treatment with blood thinning medication.
Suppressing gene may help heart pump

A gene that plays an important role in heart development has been found to also play a role in dilated cardiomyopathy (DCM).

If the gene COUP-TFII overexpresses (has a bigger effect than it should) it can cause heart function problems, say researchers at Baylor College of Medicine in Houston, America.

They have found that suppressing the gene in mice with heart failure can prolong their lives. The findings have been published in Nature Communications.

Dr Sophia Tsai, professor of molecular and cellular biology at Baylor and co-corresponding author on the study, said that mice who had overexpression of the gene had a rapid decline in health.

The mice had a similar level of gene overexpression as was seen in patients with DCM. So they decided to look into why this happened.

Dr Tsai and her colleagues also found the gene plays a role in cells that are responsible for energy production. When levels of the COUP-TFII were overexpressed it created an overload of reactive oxygen which damaged the cell causing heart failure.

When the system functions properly, COUP-TFII expression is very low. But when its expression is induced in heart disease patients, function is disrupted and the heart is damaged, said researchers.

Researchers said: "It was thought that the gene expression was a consequence of dilated cardiomyopathy, but we have found that it is part of the cause. This gives us a target for further research needed before clinical application."

The full story is on our website cardiomyopathy.org/suppressing-gene

Gene testing urged in post mortems

All young people who die suddenly from a suspected heart problem should have their DNA analysed, new European guidelines suggest.

The European Society of Cardiology (ESC) has recommended that detailed genetic testing should be a fundamental part of the post mortem examination.

Identification of a genetic cause, such as cardiomyopathy, could help ensure that relatives were quickly diagnosed and protected, the society said.

"For the first time these guidelines have incorporated the concept proposed by several documents that DNA analysis should be a fundamental component of post mortem assessment in young victims," said Professor Silvia Priori, chairman of the guidelines task force.

"The molecular analysis helps to identify genetic diseases that can occur in a structurally normal heart and therefore cannot be identified during autopsy."

For more cardiomyopathy-related news stories go to cardiomyopathy.org

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New data on scale of cardiomyopathy

A registry set up to record the scale of cardiomyopathy in Europe and how well patients do has just published its first results.

The European cardiomyopathy registry, set up by the European Society of Cardiology (ESC), is collecting comprehensive data on the disease for the first time in a bid to improve care services and treatments.

The ESC says that individually the different disorders are relatively uncommon, but together around three per 1,000 people in Europe have it, putting a substantial burden on the healthcare services of all European nations.

The first observational study looked at 1,115 patients from 27 hospitals in 12 countries added to the register between 1 December 2012 and 30 November 2013.

The commonest cardiomyopathy was hypertrophic (681 patients), followed by dilated (346), arrhythmogenic right ventricular (59), and restrictive (29); 423 patients (46.4%) had familial disease.

There were more men for all the types except restrictive.

Most patients (813) were in New York Heart Association heart function class I (no limitation of physical activity) and ordinary physical activity did not cause undue fatigue, palpitation or shortness of breath) when put on the register.

But 139 (12.5%) reported loss of consciousness, most frequently in ARVC. Nearly half (45.5%) of patients had had a cardiac MRI (magnetic resonance imaging), 117 (10.6%) a heart biopsy, and 462 (41.4%) genetic testing with a disease-causing mutation reported in 236 people (51.1%). Just over 1,000 patients (92.0%) were on drug treatments; 316 (28.3%) had an internal defibrillator (termed an implantable cardioverter defibrillator or ICD). The highest proportion of those with an ICD had ARVC.

The researchers included Professor Perry Elliott, from the Barts Heart Centre in London, and other doctors from France, Spain, Italy and Poland.

For more details, see cardiomyopathy.org/registry-data
A: TTC, also known as takotsubo syndrome, broken heart syndrome and stress-induced cardiomyopathy, was first described in Japan in 1990. It is characterised by transient deterioration in heart function caused by ballooning of the main pumping chamber of the heart (the left ventricle). The cause of TTC remains uncertain and it is likely that multiple factors are involved. TTC primarily occurs in postmenopausal women after a physical or emotional stress. It is also reported in patients with an adrenal tumour (on the adrenal glands attached to the top of each kidney). Alternative hypotheses include coronary artery spasm, drug use and inflammation. I am not aware of a connection with dengue fever per se.

Q: Recent reports in the press suggest that digoxin dramatically increases the risk of death and should be used with great caution. As someone who has been taking 62.5mcg daily for the last five years, how concerned should I be? Is there a safer alternative?

A: Digoxin is an old drug that is commonly used to control heart rate in patients with atrial fibrillation (AF), although there are few studies to support this long-standing practice. In a recent retrospective analysis of a trial evaluating a novel anticoagulant rivaroxaban (ROCKET AF trial) digoxin treatment was associated with a significant increase in all-cause mortality, vascular death, and sudden death in patients with AF. This association was independent of other measured prognostic factors, although other confounding factors could account for these results. Similar findings have been seen in trials of heart failure medication, but there is some evidence that the dose of digoxin is an important factor. For the moment, I suggest that you discuss your need for digoxin with your cardiologist, but do not stop the drug until you have done so.

Q: I've been taking the drug spironolactone now for a number of years for dilated cardiomyopathy (DCM). I've also been advised recently that I have a kidney stone and above normal levels of uric acid. Are you aware of any connection between this medication and the two symptoms?

A: Some diuretics (or water tablets) can result in elevated uric acid levels. In the case of spironolactone, there is very little information but there have been some recent reports suggesting that it may also raise uric acid. With regard to your kidney stone, you should enquire as to what type of stones you are prone to make.

Q: Is there a link between dengue fever and takotsubo cardiomyopathy (TTC)?

A: Some diuretics (or water tablets) can result in elevated uric acid levels. In the case of spironolactone, there is very little information but there have been some recent reports suggesting that it may also raise uric acid. With regard to your kidney stone, you should enquire as to what type of stones you are prone to make.

Q: Is there a link between dilated cardiomyopathy (DCM) and chronic fatigue syndrome?

A: DCM can certainly cause fatigue because it reduces the amount of blood that the heart can pump during exertion. Some of the drugs used to treat DCM (notably beta-blockers) can also cause fatigue.

Q: Is there a link between pulmonary artery stenosis (narrowing in the large artery that sends oxygen-poor blood into the lungs) and hypertrophic cardiomyopathy (HCM)?

A: In general, HCM is not associated with pulmonary artery stenosis, but there is a rare form that occurs in a condition called Noonan syndrome in which it can occur with abnormalities of the pulmonary valve and other congenital heart defects.
Getting on with life is important to us

Paul Nicholls' story

Paul found being diagnosed with dilated cardiomyopathy and heart failure daunting. But he says information he got from Cardiomyopathy UK and his local support group helped a lot.

I was checked out after suffering some chest pains in late 2012 and after lots of tests including echo, CT scan and cardiac MRI I was diagnosed with dilated cardiomyopathy the following January. I was 46.

Before I knew it, I was on the drug treatments spironolactone, nebivolol (the only beta-blocker they'd try as I'm asthmatic) and losartan (I tried ramipril first but got the dreaded dry cough). While wearing a Holter monitor, irregular heart rhythms were recorded.

Then in 2013, because doctors felt I was at risk of developing a dangerous heart rhythm, I had an internal defibrillator (ICD) fitted. My cardiologist wanted me to have one with a combined biventricular pacemaker (officially called a CRT-D) but although I ticked all the other boxes to be eligible, my heart failure symptoms weren't severe enough — according to the NICE guidelines.

This didn't last for long though. My ejection fraction (EF — a measure of how well a heart is pumping) dropped to about half what it should be and my heart became more desynchronised.

So last year I had my ICD swapped for one with biventricular pacing. Almost immediately my breathlessness disappeared and nine months after implant my EF was up from 25% to 39% — still impaired but a significant improvement.

My main symptom is still fatigue. I worked as a construction site manager but this role was proving too demanding. I worked long hours under a lot of stress. So my employer, the large construction company Kier, found another, more flexible role in the business for me as a a skills co-ordinator and I still work full time.

I try to manage my condition and life, and try not to overdo things, though I fail quite often. I make sure I take my medicines at regular times, and plan my rest and relaxation. I would recommend to others with cardiomyopathy gaining a basic knowledge of your condition. Some of the information you read can be quite negative and out of date though, and you have to remember that medicines are improving all the time as is device therapy and even transplantation.

With some lifestyle changes, I can live a near normal life, even if I am high maintenance health wise.

My wife Becky and our two daughters, Jess, aged 13, and Joy, 7, keep me motivated and busy. I’ve recently been given the all clear to start cycling again which is very liberating — even if I do need a lot of rest to recover from it.

It was daunting being diagnosed with dilated cardiomyopathy and heart failure, especially as at the time I didn’t really understand the medical terms and what they meant for me. I found things easier to accept and live with once I had a basic understanding of them. Cardiomyopathy UK and the Cornwall Cardiomyopathy Support Group have helped me to understand and accept my condition. The information day in Newquay, Cornwall was very helpful and educational, not just for me, but also for my wife.
How support groups help

Jon Comb’s story

Jon, 50, talks about how he went from being unable to walk a few yards in 2013 because of his noncompaction cardiomyopathy to taking part in the British Transplant Games.

In 2009 at the height of the swine flu epidemic, I had all the symptoms of the condition. I went to the doctors and they put me on tamiflu pills. The symptoms went after a few days but my cough persisted.

After listening to my chest two weeks later, the GP sent me for x-rays. I was then given an ECG, echo and blood tests. I was told I had left ventricular noncompaction (LVNC) and was in heart failure. It was such a shock.

In LVNC the walls of the main pumping chamber of the heart become spongy. It’s thought it develops that way while you’re in the womb. The consultant told me he didn’t know much about it and referred me to the Freeman Hospital in Newcastle.

I was put on drug treatments (beta-blockers and sartans – ACE inhibitors didn’t agree with me) and things started to stabilise. But in 2011 I had a mini-stroke, was medically retired from my job as a civil servant and doctors decided I needed an internal defibrillator (ICD) with biventricular pacing to help my heart beat in a more co-ordinated way. That was fitted in 2012. Again things improved but the following year I had lots of chest infections, one of which would not go away.

At my hospital appointment that spring, doctors told me they thought I should have a heart transplant assessment. It knocked me back, but I thought it was just an assessment. But by the time I went for it that July I was looking really blue and I was kept in hospital. Ten days later I was on the urgent list for a transplant and five days after that I got my new heart from a man in his 20s.

I woke up nine hours later in intensive care feeling on top of the world. The difference was absolutely immediate. I could feel that everything was working and my wife Win said I looked pink for the first time in years. My appetite was back and I could taste food. I ate like a horse – and still do. After five days I was back on a cardiac ward and three weeks later back home. For my first full day at home I went for a half mile walk. Previously I could not walk from my front door to my front gate. Apart from a viral infection and a couple of chest infections since, I have been fine and never felt better.

The staff at the Freeman, from cleaners to consultants, are some of the most dedicated and amazing people I have ever met. I’ve also become involved with the Freeman Heart and Lung Transplant Association and am their photographer. The group runs sports teams and raises money to buy equipment and help transplant families. I have hypermobility syndrome (my joints easily move beyond their normal range making me prone to injury). So I’ve never been sporty. But the group asked if I’d like to do some sports, especially as the British Transplant Games were coming to Gateshead this summer.

So I decided to take up archery. As the games are held over five days it was suggested that I should compete in a different event each day. So I took part in swimming, ten-pin bowling, throwing a cricket ball and the javelin. It was a wonderful experience. The atmosphere was absolutely fantastic and family and friends came from hundreds of miles to watch. Quite a few of us took part in the donor walk, including Win and my stepdaughter Heather.

I had joined the North East Cardiomyopathy Support Group when it started three years ago and it has really helped us. It is so welcoming and friendly, and we have a good laugh. It’s a tonic in itself. It’s so good to meet others with cardiomyopathy and we’ve made some really good friends. When I was in hospital Win gave an update on my progress to the group and I later made a presentation to them about my transplant. When I was at the games, group members came to cheer me on and manned a stand to promote Cardiomyopathy UK.

One friend from the group who gave me a lot of support is now facing a transplant himself and I’m trying to support him in return. My life is so blessed. And all because a family made a courageous and wonderful decision to donate their son’s organs to save others. See www.organdonation.nhs.uk/register-to-donate/

• Jon is pictured top left at the British Transplant Games with stepdaughter Heather and her baby Connor.
Jane Barnett’s story

Jane (pictured left) talks about how she and her daughters were diagnosed with hypertrophic cardiomyopathy and how starting a support group has helped her family and others.

Like many others, we lived unknowingly with hypertrophic cardiomyopathy for some years before any diagnosis was made. We were told by our GP that our daughters’ (Judy and Lisa’s) difficulties in certain areas, such as walking at a reasonable pace uphill or performing in team games at school, were a sign of asthma and they were promptly issued with inhalers.

It was not until Judy was 16 and midway through her GCSEs that a heart murmur was detected by a very astute young doctor who Judy went to see because she was suffering from a very bad cold.

We took her immediately to a local cardiologist who expressed concern and confusion over what he saw in the echo he carried out and asked if there were any siblings to be checked.

We were then told that Lisa, 14 at the time and who has since gone on to have a heart transplant, displayed similar signs on her echo. A similar diagnosis for me followed later.

It was some time before we found a cardiomyopathy specialist — Professor William McKenna, president of Cardiomyopathy UK and at the time he was based at the Heart Hospital in London.

It was still a while before we heard of Cardiomyopathy UK and the support the charity offered to families affected by the disease. Had we known about the charity and had some relevant counselling or been able to talk to people in similar situations at the time, this might have helped.

Most people we knew had not heard of cardiomyopathy. Sadly this still seems to be the case in the public at large.

Heart disease is a difficult one for young people to cope with. It was easier for me at my age to explain to my friends and family. My husband David has had to go through the difficulties of having all his closest family affected and the complications that have resulted, and learn in his own way how to deal with it.

In 2009 both David and myself attended a training day to join the charity’s network of support volunteers who talk to others by telephone and email. The network has around 80 people on it affected in some way by cardiomyopathy and we still belong.

I also decided to start a support group where we live in north London. It meets every few months on a Saturday afternoon at Finchley Memorial Hospital. We have expert speakers on cardiomyopathy and cardiomyopathy-related issues and sometimes we just have a social get-together.

My motivation in choosing to start a support group was that we know that people in many cases need to talk, if not to a trained counsellor, then to others in similar circumstances, while other people may just like to get on with it alone.

I thought that starting the support group would help me as well as others in the area, by providing professional advice in all sorts of areas. Exercise, heart failure, holiday insurance, internal defibrillators (ICDs), and counselling are among some of the topics we’ve looked at.

But above all, the group enables its members to chat and exchange experiences with one another. Some of us have known each other for quite a number of years now and so we can all empathise together.

Left ventricular noncompaction (LVNC) is a condition where areas of the heart muscle appear spongy or honeycombed. Deep channels, known as trabeculations, are present in the heart muscle wall. These channels connect directly with the left ventricle (the main pumping chamber of the heart).

In the embryo the heart muscle is made up of interwoven fibres. As development progresses these fibres compress to form the muscular walls of the heart. It’s probable that formation of the trabeculations is as a result of a defect in this process.

The condition can occur in isolation and be associated with other cardiomyopathies, particularly hypertrophic and dilated.

There is evidence the condition runs in families and so screening of close family members is advised. Controversy remains on the subject of whether LVNC can be categorised as a separate form of cardiomyopathy or is part of the spectrum of other types of cardiomyopathy. As such it remains an unclassified condition with no international guidelines on treatment. How common it is is not clear. It is considered rare though there has been an increase in the numbers being diagnosed in recent years because of improved imaging techniques. It is estimated that up to 24 people per 100,000 are affected, though this is probably an underestimation. It is diagnosed by echo, with subsequent magnetic resonance imaging (MRI) to confirm the diagnosis.

As LVNC cannot be cured, the treatment aims to alleviate symptoms, though some people have no symptoms. A comprehensive clinical history and diagnostic testing (such echo and MRI) are essential to determine the appropriate treatment for the individual. Therapy reflects the extent of and the position of the trabeculations. Treatment focuses on improving the heart’s function and preventing complications. If LVNC occurs with another type of cardiomyopathy, this may need to be treated too.

In some people, there may be a risk of blood clots forming in the trabeculations, which could increase the risk of a stroke if they entered the bloodstream. Blood thinning drugs, such as aspirin, or anticoagulants, such as warfarin, may be used to reduce this risk. This remains controversial but anticoagulants are now more commonly prescribed if patients also have reduced left ventricular function.

Arrhythmias, such as heart block (where electrical impulses are not being transmitted effectively to the lower chambers — the ventricles) resulting in a low heart rate, may occur and a pacemaker might be required. There may be cases where there is an increased risk of sudden death and an implantable cardioverter defibrillator (ICD) would be used. If the condition has resulted in a reduction of the heart’s pumping action then national guidelines on treating heart failure would apply and diuretics, beta-blockers and ACE inhibitors or angiotensin II receptor blockers (ARBs) would be used. A biventricular pacemaker may also be needed. Treatment plans must be devised to meet the needs of the individual.
Genetic basis of dilated cardiomyopathy to be studied

Researchers have been given a large grant to study the genetic basis of dilated cardiomyopathy (DCM). The $12.4 million US project is designed to help doctors better understand the inherited condition and help prevent the disease developing in family members.

With the money, the researchers at Ohio State University's dilated cardiomyopathy consortium will look at the characteristics of the disease in 1,300 DCM patients and up to 5,200 family members. The team will perform gene testing, looking at all the patients' genes, to try to find the disease causing mutation in each family so more family members at risk of developing the disease can be identified.

“We believe the new information will help doctors understand DCM as a genetic disease,” said lead investigator Dr Ray Hershberger. He said the new insight would also help prevent family members getting the associated health problems and the risk of early death from heart failure. Collaborating in the consortium are researchers from many other hospitals, including children’s hospitals. The money comes from the country’s medical research agency.

For more details, see cardiomyopathy.org/DCM-study

New heart failure drug available to some

The new heart failure medicine Entresto is now available for some people seriously affected by the condition. The drugmaker Novartis has announced the drug, also called sacubitril-valsartan or LCZ696, is being made available to the NHS under the Early Access to Medicines Scheme (EAMS).

This scheme aims to give patients with life-threatening or seriously debilitating conditions access to medicines that do not yet have a marketing authorisation. Novartis says the drug is the first non-cancer drug to gain the EAMS status under the Medicines and Healthcare Products Regulatory Agency's programme for innovative medicines. The company can provide the drug to eligible patients before a final European licensing decision is made.

“This is great news for patients with heart failure,” said Professor Iain Squire, Professor of cardiovascular medicine, University Hospitals of Leicester NHS Trust. He added: “Based on what we’ve seen in clinical trials, access to this new medicine will help patients live longer and keep them out of hospital, compared to currently available treatment.”

Entresto is a twice-a-day tablet which is designed to enhance the protective neurohormonal systems of the heart while simultaneously suppressing the harmful system.

Hugh O'Dowd, general manager at Novartis UK & Ireland, said: “We are working closely with the NHS to ensure eligible patients have rapid access under the scheme while we await the final European licensing decision.”

For more details, see cardiomyopathy.org/heart-failure-drug

More families may soon benefit from IVF technique

More families affected by dilated cardiomyopathy (DCM) may soon be eligible for IVF treatment to ensure their babies are not affected.

The Human Fertilisation and Embryology Authority (HFEA) is looking at whether to license pre-implantation genetic diagnosis (PGD) for DCM families affected by mutations on the CMD1A gene.

PGD is a technique that enables a couple with a specific inherited condition in their family to avoid passing it on to their children. It involves checking the genes of embryos created through IVF. Then only those embryos without the gene mutation are implanted in the mother’s womb. The CMD1A mutations are particularly linked to electrical conduction abnormalities in the heart and muscular dystrophy.

The HFEA has already licensed PGD for DCM families affected by mutations on the Troponin T2 gene, those with hypertrophic cardiomyopathy caused by mutations on the MYBPC3 gene, and those with arrhythmogenic right ventricular cardiomyopathy.

PGD is designed to give families with a serious disease the chance to have IVF and PGD if they know the gene mutation causing the disease in their family. Cardiomyopathy UK and the Genetic Alliance UK are making a joint submission to the HFEA in favour of the new licence. Members of the public can also have their say by emailing pgd@hfea.gov.uk.

For more details, see cardiomyopathy.org/ivf-help

General population heart checks not recommended

The UK National Screening Committee has again decided that heart checks for all young people are not necessary. The committee considered heart screening for people aged between 12 and 39 to prevent them dying suddenly from heart conditions such as cardiomyopathy.

The committee said it did not recommend systematic screening because:

Currently there are uncertainties over the test, the conditions that can cause sudden cardiac death (SCD), and the overall benefit of identifying those at risk when weighed against potential harms;

There is very little research into the reliability of the tests for identifying those at risk of SCD;

There is no agreed treatment or care pathway for supporting those who have been identified as at risk of SCD;

Someone who is identified as having a high risk of SCD may become anxious about their physical activity and stop regularly exercising which can be detrimental to their overall health.

Cardiomyopathy UK chief executive Robert Hall said: “We support the committee's stand. Rather than screening all young people, we believe many more lives can be saved in people of all ages by raising awareness of the condition with GPs, improving cardiology and emergency care, and more widespread availability of gene testing.”

CMAA editors’ note—For IVF testing information in Australia, go to www.ivf.com.au or enter “preimplantation genetic diagnostic testing” in Google. It appears that testing for HCM and DCM may not be supported. Please note, your editors are merely giving information readily available on the net and neither recommending nor suggesting IVF.
CMAA Library
Books and DVDs are available from our Library for members’ information.

Books:
Living a Healthy Life with Chronic conditions by Long, Sobel, Laurent
Inherited Heart Conditions Ventricular Cardiomyopathy
Inherited Heart Conditions HCM & Inherited Heart Conditions DCM

DVDs:
DCM… The Facts       HCM…. The Facts
One life a Second Chance        ‘HAS
Cardiomyopathy Heart Failure ‘Speaking from experience.’ CMAA
Preventing Sudden Cardiac Arrest.. (Medtronic)
Living with CM       CMAA    Dr Lindsey Napier 2005
A Multi Disciplinarian Approach to CM  Professor Sindone 2006
Chronic Heart Failure  CMAA Dr C de Pasquale  2004
HCM       CMAA     Dr Mark Ryan
Maintaining Heart Health  Dr E Barin 2004

CMAA Conference DVDs:
Sydney ‘Cardiomyopathy What’s Working’ 2010
Brisbane ‘Cardiomyopathy a Moving Picture’ 2012
Melbourne ‘Cardiomyopathy Keeping you on track’ 2014

Books are returnable but DVDs are Non returnable.
A small Donation would be appreciated towards running the Library

Cardiomyopathy Australia

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