

**LONG TERM CONDITIONS E-NEWS**

May 2016

**LoCAL NewS**

We need your help to design future healthcare services for people living with a long-term condition

Help us find solutions that mean our services can keep people independent and able to manage their own condition, such as diabetes, with professional support, both now and in the future

**Thursday 5th May 10.30am- Lakeside Park**

**1pm Wootton**

**Tuesday 10th May 2pm- West Wight Sports**

**4.30pm Centre, Freshwater**

**Friday 13th May 10.30am- YMCA, Winchester**

**1pm House, Shanklin**

For more information or to confirm your attendance, please call 01983 822099 x 3085 or email [MLAFL@iow.gov.uk](mailto:MLAFL@iow.gov.uk). Visit our website [www.mylifeafulllife.com](http://www.mylifeafulllife.com)

**Dana Edkins, Heart2Heart Support Group member’s 4 Day Challenge**

In 2014 Dana and her friend shaved their heads, for the British Heart Foundation. This time she is taking the challenge to a new level!

On Friday the 6th of May, European Heart Failure Awareness Day, at 10 am outside the British Heart Foundation shop in Newport, Dana and two others including Georgina (Heart Failure Specialist Nurse) are going to set off on a journey to leave the Island without money, food, transport, or mobile phone, just a back-pack and sleeping bag. They will be relying on the generosity of travel companies, hotels, restaurants and the general public to feed and shelter them on their journey. They are doing this challenge to raise money and awareness for five chosen charities close to their family and friends. The charities are British Heart Foundation, Pumping Marvellous, JDRF (Juvenile Diabetes Research Foundation), IOW Youth Trust & YMCA Young Carers IOW.

In 2010, Dana was diagnosed with a rare genetic heart condition called ARVC which has changed her life a great deal, including the need to have an ICD fitted as she is at risk of cardiac arrest. The condition attacks the heart muscle and she is therefore in stages of heart failure for which there is no cure and in time will need a heart transplant and palliative care.

Let us all help Dana raise as much money as possible for this amazing if not crazy challenge!

You can follow her on twitter @iow\_challenge.

You can donate on http://www.virginmoneygiving.com/team/4isleofwight.

There is also a raffle on the 13th May, and they have over 70 brilliant prizes including Festival and Bestival Tickets, this is being held at the Castle Inn Newport at 7pm. Tickets are available on the night or from Dana: [dana101@btinternet.com](mailto:dana101@btinternet.com)

Let’s wish her lots of luck and hope she raises a lot of money.

**Healthwatch Prioritisation Survey**

Healthwatch Isle of Wight is an independent consumer champion; set up to listen to the voice of the local community. We work with others to make improvements to health and social care services. They are running a survey to find out what the people of the Island would like them to focus on over the next eighteen months. You can complete the survey by linking on the link below. All returned entries will be added into a draw for a £25 Love2Shop voucher.

<https://www.surveymonkey.co.uk/r/VX7NYG8>

**Blind and partially sighted people in the Isle of Wight offered specialist support at point of diagnosis**

A new service providing emotional and practical support to people who have just found out they’re losing their sight has been set up by sight loss charity Action for Blind People, in partnership with the Isle of Wight NHS Trust.

Blind and partially sighted patients will be offered the specialist support through the newly appointed Eye Clinic Liaison Officer (ECLO), Laura Gardiner. Laura has been appointed to the Ophthalmology Department at St. Mary's Hospital for 12 months to support patients who have recently been diagnosed or have existing sight loss.

ECLOs, also known as Sight Loss Advisers, work alongside health professionals, offering help and advice on a range of areas including independent living, returning to work, benefit entitlements, offering advice on coping at home, and emotional support.

Laura Gardiner, Eye Clinic Liaison Officer for Action for Blind People, said: “I lost my sight five years ago and understand the importance of having that dedicated support. Being based in the eye clinic gives me the ability to spend time with people, talking through their diagnosis and supporting them to maintain their independence.”

Loraine Brown, Team Leader for Action for Blind People said: “It can be an overwhelming experience to be told you are going to lose your sight. That feeling is compounded if people have to deal with it alone. ECLOs provide much needed information, advice and guidance and we are pleased to be working with Isle of Wight NHS Trust to provide the ECLO service.”

Kathryn Taylor, Isle of Wight NHS Trust Operational Manager, said: "This dedicated support is especially important as the number of people with sight loss is set to increase significantly over the next 20 years. NHS England has launched a national call to action to change how we deliver eye services in the NHS and we are really pleased to be working with Action for Blind People to improve support services for patients on the Island.”

RNIB (Royal National Institute of Blind People) and Action for Blind People are calling for every eye department in the UK to have access to an ECLO.

**TRAINING**

At Community Action we have a selection of training events for not-for-profit organisations on the Island which I hope will be of interested to you.  To book places on any of these sessions please complete and return the attached booking form to [hello@actioniw.org.uk](mailto:hello@actioniw.org.uk)  Details of our training can be found on [**our website**](http://www.communityactionisleofwight.org.uk/what-we-do/support-for-voluntary-groups-charities/training/)

Subject to interest we may limit the number of places per organisation but initially places will be allocated on a first come, first served basis.

**Insurance for not-for-profit groups – Free**

Fri 6th May, 10:30 - 12:30

Norris and Fisher insurance brokers will shed light on employer’s liability, public liability, trustee’s indemnity etc. by explain the types of insurances that not-for-profit organisations should have in place.  There will be lots of opportunities to ask questions.

**New Code Continue and Begin Fast Coaching – Free**

Wed 18th May 9.00 to 4.00

This is a one day course that will give you skills as a coach that you can use in both your personal life and in your role within your support group. Please bring your own lunch.

Contact Sara Ellis at Community Action for more details

**Planning and Running an Event - £25**

Tues 10th May, 09:30 – 12:30

Looking to hold your first event this summer?  Then this is a great starting point.

**First Steps to Successful Volunteer Management £35**

Wed 15th June, 09:30 – 16:30

This is a full day of training for people new to managing volunteers.

**Managing Difficult Volunteer Situations - £25**

Wed 6th July, 09:30 – 12:30

Unfortunately, when managing volunteers sometimes difficult situations arise.  This short course will help you be better prepared and know what to do.

This bulletin will be produced on a bi monthly basis as part of the Long Term Condition Self Help Group development programme co-ordinated by Community Action IW.

For more information contact Claire Tillman, Project Co-ordinator on [ctillman@actioniw.org.uk](mailto:ctillman@actioniw.org.uk)

Community Action Isle of Wight, Riverside, the Quay, Newport, Isle of Wight, PO302QR.

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