

A large, semi-circular graphic on the right side of the page featuring a close-up of several blue forget-me-not flowers with yellow centers, set against a dark blue background.

# A good life with Dementia



Caring, Learning  
& Growing Together



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# Introduction

**This post diagnostic resource pack came out of the delivery of the Good Life With Dementia course, a post diagnostic course which itself was created and delivered BY people living with dementia in East Riding FOR people living with dementia in East Riding.**

The course answered the many questions that people recently diagnosed with dementia had about their diagnosis, about the future, about the implications of it on their lives and relationships; and on their confidence and their rights to continue as valid and valued members of their neighbourhoods and communities.

We knew it would answer the questions people had because it was put together by local people with dementia sharing the key messages they wanted to give to people going through diagnosis, drawing on their own experience having gone through that same local process. Who better to learn from than those who have been there and got the T-shirt!

As well as key important local information and numbers to contact gathered from the course, it contains a powerful 'manifesto' of what local people with dementia expect and demand; a list of what was learnt on the course; and an invaluable 'must read' insight into 'what my dementia means to me'.

Local services and providers have requested this resource. They realise that, however well-intended, much of the information they currently provide themselves has been created by them for others – essentially a best guess. This resource, however, has been created by and with people living with dementia themselves, and has been born of their real experiences.

The Good Life course in East Riding has also led to the creation of a new group of peers with dementia, who are now meeting regularly – the East Riders! Thanks to the forward-thinking collaboration from across health, social and third sector across East Riding, we shall be co-creating more Good Life courses – and consequently more groups of peers who can form a growing network of active engaged people with dementia across the region.

# Our Manifesto

## The Course

The course has helped make meaningful connections. To say 'Ahoy there!' to fellow sailors, to support and encourage each other and to share the simple joys of a dog walk on the beach.

It's nice just being amongst people with a shared experience – not being talked at by **other people** like a child

## A message to all about our needs, rights and expectations

### Just so you know

'Dementia'. It's not our fault, it's nothing to be ashamed of and there is still a life to be lived!'

'Coming out' and sharing our diagnosis with others can be a weight off our shoulders

We often leave doors open. It may well be so we don't forget what's on the other side!

Dementia is my new 'normal' – something that no-one wants but something we have to be positive about and get on with as well as possible.

I need time and space to be involved in a project to keep me going it is a **MUST** to have our own hobbies.

## A message for our care partners and allies

Let go of the fear of letting us do some things for ourselves.

I'm still me. Just be patient, tell me you love me and, politely, remind me that I've forgotten to put my trousers on!

Initially I would blame others thinking they were trying to make me look foolish. Please bear with us and acknowledge our feelings.

Sometimes if I get something wrong it can be like stirring a hornets nest - Don't sting us!

## Our needs and rights

Following diagnosis, we all seemed to be left to our own devices to discover how to get on actually living with this condition. **That's not right.**

Dementia can make us feel like withdrawing if we make a mistake. Please don't rub it in - it's not our fault!

It shouldn't take 5 years to get a diagnosis, even if dementia is not initially suspected.

Dementia has brought with it a huge blow to our confidence. Please don't make it worse!

We are ALL still citizens of the East Riding. We have a right to access any community facility like anyone else – so no exercise or activity is beyond our reach! – the gym, the pool, the library, the shop, the bus, the bingo, the beach is for anybody.

# What We Learnt

## WEEK 1 - There IS life after a diagnosis of dementia

- All the questions and issues we had matched the course content. Of course! Who better to put a course together than people who've been there and got the t-shirt?!
- It's good to hear it wasn't just me who had problems and a long journey accepting the diagnosis.
- 'a label of dementia, it's not our fault, it's nothing to be ashamed of and there is still a life to be lived!'

## WEEK 2 - It's NOT your fault!

- It's important to be 'keeping on doing', aware that the future might bring challenges ahead.
- 'Put me on a beach with a dog and I'm happy'

## On moving House or changing environment this might help

- Lots of post it notes on doors and labelling boxes.
- Keeping an important box (with tea, kettle and bottle of brandy!).
- Photos on cupboards of the inside of those cupboards.



## On finding your way around a new area this might help

- Life360 – a ‘Family locator and GPS tracker’ app.
- ‘What3Words’ – an app to help identify precise locations.
- Use of google maps.
- Do a test journey and take photos along the way.
- Always carry your new address in your pocket.
- If all else fails, follow the dog home!
- Dementia and medication can affect our sleep patterns. We all have unique sleep patterns. It’s always worth consulting the GP with any questions about managing your meds.

## A little about the Brain

- We can see it as a set of fairy lights. Different lights flicker and fade in different parts at different times.
- Some of us may have problems with balance, others with depth perception, others with putting names to faces.
- It’s much more than memory loss.

# What We Learnt

## WEEK 3 - Living with dementia - It's a two way street

The biggest lesson me and my daughters learnt was the importance of talking – to find out what we are all thinking and feeling, and it has to be two way!’

### On sharing one's diagnosis

- People will most probably already know something isn't quite right and will feel relieved to know.
- Don't let dementia have you under the thumb. There's certainly no shame about it.
- If others close to you have shared stuff with you then don't be afraid to share this.

## WEEK 4 - Always look for the smiling faces

- The Sunflower lanyard can be really useful at train stations, airports and shops. People do see it and respond by offering help.
- 'That was excellent and so detailed. I can't remember any of it but I know it was good!' - On the advice about welfare benefits!
- For ANY help with advice around benefits two words:  
**Call Christine!! – 01482 394751**

## **WEEK 5 - If you don't use it, you lose it!**

- Exercise will help ANY condition.
- It is recommended to do about 150 minutes (2 ½ hours) each week. – this could include gardening, hoovering or washing the pots. Use it or lose it!
- Don't sit for too long – get up every 20 minutes or so to potter around.

## **WEEK 6 - We shouldn't have to fit into services. They should fit in with us!**

- There are brilliant opportunities to get involved in a whole range of research locally and nationally. It's not all test tubes and white coats!
- We learnt about all the stuff for carers that should be equally available for people with a dementia! Drop in opportunities and a conference, now that would be a thing!

# What Does My Dementia Mean To Me? – Bob Long 2021

Hmm! That's a big ask!

My first thought (after, of course, considering that, in spite of my 'inner wishes', I have to acknowledge a diagnosis of dementia!) was that, progressively, I have become less able to be as 'comfortable' in respect of making proactive positive decisions. Hence I am more inclined to 'withdraw' in circumstances where once I would have offered a response around personal feelings, advice, opinion, thoughts, reflections, perhaps counselling.

I suggest that may be an 'outcome' of a long and very happy Primary School career! My teaching 'mantra' was, simply, *'when you speak I will listen, I respect what you say'*. This is a line from our school song 'This Is Our School' which was sung regularly. (*My words set to music by a very talented member of staff*).

Anyway, I have now had enough experience of personal 'inappropriate' behaviour to recognise that I need to be a careful listener before I respond to other people's thoughts, ideas, passions, decisions etc. before 'expounding' my views! I guess that, generally, (Sue may not agree!) this is why I 'walk behind', not necessarily in fear of my own integrity (and personal wellbeing) but, (this is a hopeful 'belief'!) that I don't embarrass the company around me! I suppose, to some extent, that's a 'cop-out' and, on reflection, enhances the 'analysis' and definition of my dementia.

## *Who is kidding who?!*

And the positive? Mmm! Not many in terms of returning to the 'old' Bob! However, certainly since I've 'come out' (!?) I am more easy on myself and the 'understanding' displayed by my family and friends has 'soften' and grown!

Certainly there are 'bad, sad' bits and, in respect of the times I 'default', I am always later aware of its effects on and responses from my loved ones (*so sorry Suzie; your patience is incredible!*) when the 'clouds' roll over and I lose my 'me'! That 'me' is now much too often! From the simple *'where did you put it?'* to the *'that's got to be done again!'*

Anyway, that's my 'today' reflection. It's been 'cathartic' in terms of 'emptying my head' and, having read it to Sue (and her not sending me off to try again!) I am happy to have shared it with you.

I'm still Bob. Just be patient, tell me you love me and, politely, remind me that I've forgotten to put my trousers on.

**Thank you. Bob.**

# Welfare Rights, Entitlements and Support

For all welfare rights advice in East Riding, the first number to dial for detailed information and advice is:

**The East Riding Welfare Visiting Team  
on their direct line: 01482 394633**

Christine Craven who spoke so brilliantly at our Good Life course is happy for you to contact her direct here:

**Chris Craven**  
**Email: [Chris.Craven@eastriding.gov.uk](mailto:Chris.Craven@eastriding.gov.uk)**  
**Direct line: 01482 394751**

Here is a summary of Christine's information shared with us:

**If you are at the age of receiving your pension and you have dementia:** Then you are entitled to **Attendance Allowance**.  
(AA – either lower rate £60 or higher rate £89.60/week)

**If you are younger (not receiving your pension):**  
Then you are entitled to **Personal Independence Payments (PIP)**

Both AA and PIP are NON-MEANS TESTED. Christine's team can help you set the ball rolling with the Department for Work and Pensions. (DWP)

- They are both long forms and ask you to report on all the things you need help with.
- You SHOULD get awarded either of these because of your diagnosis.
- It is important to mention all the right 'buzzwords' around needing attention and support.
- If your claim is declined you must appeal within 1 month and you need to ask for a **'reconsideration'**

**Once you are awarded either AA or PIP** you are entitled to a council tax disregard on the grounds of 'severe mental impairment'.

- If you are part of a couple you receive 25% discount.
- If you live on your own you receive 100% discount
- If there are more than 2 adults in the house, you receive no discount.

### **Your care partner may be entitled to Carer's Allowance**

**(£67.70/week)** They need to be earning less than £128/week and be caring for at least 35 hours/week.

If they're already drawing a pension then they will not be able to receive their carer's allowance as essentially these are both wage substitutes and you can only have one.

[www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance).

The welfare visiting team can complete this form for you

## Other sources of support:

- **If you use a wheelchair indoors:** you can be moved down a band in your council tax (this is a 'disablement band reduction') The welfare visiting team can complete this form for you
- **If you tell your energy supplier about your diagnosis:** They can give you a 'Priority Service' – eg they will get in touch direct in the event of repair works or a power cut.
- **If you tell Yorkshire Water about your diagnosis:** they can cap your rate for you if you are having to use more water than usual. <https://www.yorkshirewater.com/bill-account/help-paying-your-bill/> or telephone 0345 1 299 299
- **If you are in receipt of Pension Credit** (Christine's team can help check for this) **and you are over 75:** you qualify for a free TV license. The welfare visiting team can complete this form for you.



## Contact the East Riding Council for the following services:

- **Yourswitch.** Romney Clayton (01482 395380) at the Council can help negotiate for and help you switch to better Gas and Electric services
- **Blue badge scheme.** Doesn't matter how fit you are if you can't see or remember where you've parked your car! You have a right to apply though that does not guarantee success! The Council website states the following about hidden disabilities:

*'Due to the nature of non-visible (hidden) conditions, we will assess your application by looking at your needs and you will be expected to provide evidence, such as a diagnosis letter, appointment letters, prescriptions or a care plan'*

<https://www.eastriding.gov.uk/environment/roads-streets-traffic-and-parking/parking/blue-badge-parking-permits/>

- **Lifeline service:** [www.eastriding.gov.uk/living/care-and-support-for-adults/help-to-live-at-home/staying-independent-at-home-lifeline-and-responder-service/](http://www.eastriding.gov.uk/living/care-and-support-for-adults/help-to-live-at-home/staying-independent-at-home-lifeline-and-responder-service/)

## Information on the process of reporting to the DVLA.

Key steps from the Government  
[www.gov.uk/dementia-and-driving](http://www.gov.uk/dementia-and-driving)

### 1. You MUST tell DVLA if you have dementia

This does NOT mean you automatically lose your license. You let them know by filling in the CG1 form  
[assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/777292/cg1-medical-questionnaire.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/777292/cg1-medical-questionnaire.pdf)

### 2. The DVLA will get back to you

They should get back to you within 6 weeks and they may:

- Contact your doctor or specialist
- Arrange for you to be examined
- Ask you to take a driving assessment, eyesight or driving test.

### 3. They will decide one of the following

- a) you need to get a new driving licence
- b) you can have a shorter licence - for 1, 2, 3 or 5 years
- c) you need to adapt your car by fitting special controls
- d) you must stop driving and give up your licence

#### **4. If you disagree with DVLA**

You can write to DVLA at;  
DM Business Support, D7, DVLA, SA99 1ZZ

##### **You must provide**

- relevant information that was not included originally
- proof that you meet the required standards for driving
- the reference number from your decision letter

#### **5. If you want to appeal the decision**

You can contact your local magistrates court within 21 days.

You may want to get legal advice at [www.gov.uk/find-a-legal-adviser](http://www.gov.uk/find-a-legal-adviser) before you appeal - you might be able to get legal aid to pay for it (see [www.gov.uk/check-legal-aid](http://www.gov.uk/check-legal-aid)).

You must tell DVLA in writing if you choose to appeal here:  
DVLA, Drivers Medical Group, Swansea SA99 1DF



# Dementia Research

Would you like to help us by getting involved in research around dementia?

This may benefit you directly or other people in the future.

If you'd like to know more, with no obligation, please contact our friendly research team at:

**Research Team**  
**Humber Teaching NHS Foundation Trust**  
**Trust HQ**  
**Willerby Hill**  
**Beverley Road**  
**Willerby**  
**HU10 6ED**  
**Tel: 01482 301726**  
**Email: [HNF-TR.ResearchTeam@nhs.net](mailto:HNF-TR.ResearchTeam@nhs.net)**

We offer the opportunity for people to take part in many different types of dementia research. Some studies ask about health and well-being, or investigate genetics, and some gain people's experiences.

Often studies trial new methods of support or therapy, or they test new technology and each study will vary in their length and commitment. When testing a new form of support then we may 'follow' someone over a period of time to identify any changes, or they could just be involved in a short 'one off questionnaire'.

There is a study for everyone and taking part in research provides people with a chance to voice their views.

Most of our studies are adapted so that people can take part in their own homes, or over the telephone or on the computer.

The Humber Research Team have produced an animation video 'My Research Journey' which can be viewed at [www.youtube.com/watch?v=3yl8Ax3g\\_0M](https://www.youtube.com/watch?v=3yl8Ax3g_0M)

You may also be interested in:

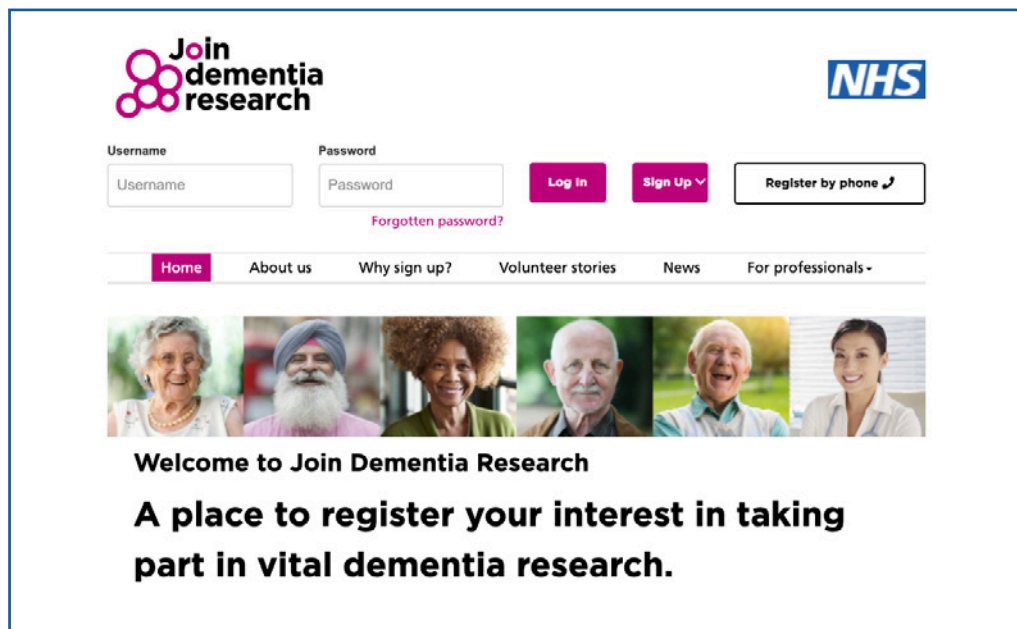
**'Join Dementia Research' (JDR)** - a national service that matches 'volunteers' to current dementia research studies, either locally or nationally. Anyone over the age of 18 can join the register– you don't need to be living with dementia.

Registration is very simple – just a few details about you or the person you are registering are required to join the register and enable a ‘study match’. This can be done ‘online’, over the telephone or by completing a leaflet and returning by post.

There is more information about JDR via a You Tube video:  
[www.youtube.com/channel/UC\\_JuNd2Cn5fmFiAqurA2R6A](http://www.youtube.com/channel/UC_JuNd2Cn5fmFiAqurA2R6A)

To sign-up please visit [www.joindementiaresearch.nihr.ac.uk/](http://www.joindementiaresearch.nihr.ac.uk/) or contact our Research Team.

Leaflets are available from the Research Team and they can also help people to register their details too.



The screenshot shows the homepage of the 'Join dementia research' website. At the top left is the logo, which consists of three overlapping circles in shades of pink and purple, followed by the text 'Join dementia research'. At the top right is the NHS logo. Below the logo is a login section with two input fields: 'Username' and 'Password'. To the right of these fields are two buttons: 'Log in' and 'Sign Up' with a dropdown arrow. Further right is a button that says 'Register by phone' with a telephone handset icon. Below the input fields is a link that says 'Forgotten password?'. A horizontal navigation bar is located below the login section, with 'Home' highlighted in a pink box. Other links in the bar include 'About us', 'Why sign up?', 'Volunteer stories', 'News', and 'For professionals'. Below the navigation bar is a row of six small portrait photographs of diverse individuals. At the bottom of the page, there is a large heading that reads: 'Welcome to Join Dementia Research' followed by 'A place to register your interest in taking part in vital dementia research.'







# Important Numbers and Websites

The East Riding Welfare Visiting Team is on 01482 394633

Christine Craven who spoke so brilliantly at our Good Life course is happy for you to contact her direct here: this is a great first step to take!

**Chris Craven**

Email: [Chris.Craven@eastriding.gov.uk](mailto:Chris.Craven@eastriding.gov.uk)

Direct line: 01482 394751

A more detailed handout has been sent as part of your resources.

For information on how to **get involved in Healthy activities and exercise sessions** contact the excellent:

**Nicola** at [nicola.parker@eastriding.gov.uk](mailto:nicola.parker@eastriding.gov.uk) or

**Sarah** at [Sarah.johnson@eastriding.gov.uk](mailto:Sarah.johnson@eastriding.gov.uk)

**Katie Gilgallon from the Humberside research team** is happy to support you to get involved in research opportunities locally and nationally. A great way to be recognised for your expertise!

**Tel: 01482 301726**

Email: [HNF-TR.ResearchTeam@nhs.net](mailto:HNF-TR.ResearchTeam@nhs.net)

The East Riding Carers service DO have a cottage and caravan available for families and you can contact them on **0800 917 6844** to see if you sneak in with your care partner!

**Margaret McHugh is from Alzheimer's Society.**

[Margaret.McHugh@alzheimers.org.uk](mailto:Margaret.McHugh@alzheimers.org.uk)

If you would like to talk to a Dementia Adviser or a Dementia Support Worker please ring **01482 211255** and leave a message or email us

[hulleastriding@alzheimers.org.uk](mailto:hulleastriding@alzheimers.org.uk)

**Amanda Hannen** Dementia Support Services Manager from Dementia Forward covering Pocklington is on **03300 578 592**

**Email:** [info@dementiaforward.org.uk](mailto:info@dementiaforward.org.uk)

**Website:** [www.dementiaforward.org.uk](http://www.dementiaforward.org.uk)

## Helpful sites on the internet.

### Tip Share.

A resource of tips FOR people with dementia BY people with dementia.

You can access it here: [dementiatip-share.org.uk](http://dementiatip-share.org.uk)

### Active East Riding site.

[www.activeeastriding.co.uk/active-together/](http://www.activeeastriding.co.uk/active-together/)

### Driving.

Information on the process of reporting to the DVLA.

Key steps from the Government

[www.gov.uk/dementia-and-driving](http://www.gov.uk/dementia-and-driving)

A more detailed handout has been sent as part of your resources

To sign-up to the national research programme **Join Dementia Research** please visit [www.joindementiaresearch.nihr.ac.uk/](http://www.joindementiaresearch.nihr.ac.uk/) or contact Katie Gilgallon on: **01482 301726** and her team who can also help you to register your details too.

## Alzheimer's Society - What do we offer?

Dementia Support Workers and Dementia Advisers offer information, advice and support to anyone affected by dementia.

This can be by phone, email and in person. We can visit you at home, at a nearby health venue or at a mutually agreed place near your home.

If you would like to talk to a Dementia Adviser or a Dementia Support Worker please ring 01482 211255 and leave a message or email us [hulleastriding@alzheimers.org.uk](mailto:hulleastriding@alzheimers.org.uk)

### Activity Groups in East Riding

Our Activity Groups are now taking place across East Riding. Each group meets monthly for a couple of hours and gives you the opportunity to take part in activities decided by the group, in a relaxed informal environment. Refreshments are available and there is no charge to attend.

The groups are held in Beverley, Market Weighton, Hessle, Preston, Bridlington, Willerby and Driffield and Goole. If you would like to find out more and see if there are spaces available at the group you would like to attend, please ring us on 01482 211255 and leave a message or email us [hulleastriding@alzheimers.org.uk](mailto:hulleastriding@alzheimers.org.uk)

## **Dementia Connect Online support**

There is tailored online support at [dementiaconnect.alzheimers.org.uk](https://dementiaconnect.alzheimers.org.uk) available 24 hours a day. You answer a few simple questions about yourself – or someone you know – to get personalised, relevant information and advice, including the option to request a call from one of our dementia advisers.

## **Talking Point**

Dementia Talking Point is our online community where anyone affected by dementia can ask questions, get information and share practical tips with people who understand.

People can connect with someone who is going through a similar experience, receive valuable support, and feel less isolated. It's free, available 24 hours a day and accessible via smartphone, tablet or computer.

You can remain anonymous when using Dementia Talking Point, to discuss sensitive issues about dementia and seek support more privately.

Join the community today at [www.alzheimers.org.uk/talkingpoint](https://www.alzheimers.org.uk/talkingpoint)

## **Dementia Voice**

Dementia voice offers opportunities to people affected by dementia to use your personal experiences to help shape the work that Alzheimer's Society does. It is also often referred to as 'user involvement'.

To find out more visit:

[www.alzheimers.org.uk/get-involved/dementia-voice/what-is-dementia-voice](https://www.alzheimers.org.uk/get-involved/dementia-voice/what-is-dementia-voice)

## Dementia Together magazine

Dementia together is the magazine for you, whether you're raising funds, creating dementia-friendly communities, campaigning or living with the condition in your day-to-day life.

Our real-life stories and updates will keep you in touch, and the ideas packed into every issue will help you take action to make a difference. Download from the website or subscribe for a hard copy.

To find out more visit

[www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together-subscribe](http://www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together-subscribe)



# Healthy Exercise

Here is some useful information about exercise programmes that was provided to us by the excellent Nicola and Sarah from East Riding leisure. All programmes require a referral from your medical professional.

## Exercise Referral Programme (£33)

**Full membership • Gym • Pool • Classes**

### **Daytime racquet sports (9am - 4pm)**

A 10 week programme providing activities to improve your medical condition. One to one sessions with a fitness professional progressing into small group gym based sessions.

## Get Fit For Your Operation - HOP Programme (Funded)

**Full membership • Gym • Pool • Classes**

### **Daytime racquet sports (9am - 4pm)**

A 4 to 28 week programme. The aim is to improve overall health in preparation and recovery of non-emergency surgery. Weekly sessions with a dedicated fitness professional addressing exercise, nutrition and lifestyle choices.

## ESCAPE PAIN Hip and Knee or Back Care Programme (£19.80)

**Full membership\* • Gym • Pool • Classes**

### **Daytime racquet sports (9am - 4pm)**

**\*induction will be chargeable for the gym**

A pain management programme for 6 weeks offering two weekly sessions. The group sessions are made up of 20 minutes education followed with a 40 minutes circuit, working at your own pace with a professional dedicated instructor.

## Cardiac Rehabilitation (£4 per session)

**Gym only • At structured times**

**(varying across East Riding Leisure sites)**

An 8 week circuit based programme, offering two weekly group sessions post cardiac event or surgery. Exercises are tailored to the individual, in a safe and controlled environment, with a qualified cardiac rehabilitation instructor.

**For further information contact:**

**Phone: (01482) 395223, Email: [leisure.health@eastriding.gov.uk](mailto:leisure.health@eastriding.gov.uk)**  
or speak to your medical professional.

Aged 40 to 74  
years old and  
not had an NHS  
Health Check?

**NHS  
HEALTH  
CHECK**

Helping you prevent

diabetes

heart disease

kidney disease

stroke & dementia

Book online [www.eastringleisure.co.uk](http://www.eastringleisure.co.uk)

# Thanks to our Contributors



Ahmad



Bob



Wendy

Resource Pack produced in partnership with:

**Rotary**  
Club of Weighton Wolds



**Innovations  
in Dementia**



**EAST RIDING**  
OF YORKSHIRE COUNCIL