

North Devon Integrated Diabetes Service Patient Engagement Report

The North Devon Integrated Diabetes project team is engaging with patients throughout the development of the new service.

Patients have been engaged in four ways, being involved in:

1. Project Team meetings
2. Patient Focus group meetings
3. Individual patient engagement through:
 - Detailed patient interviews
 - Patient questionnaires
4. Project assurance by means of the local Diabetes UK group booked in January 2018

This report outlines the result of that engagement that has taken place from January to August 2017.

We carried out a survey with the North Devon Diabetes Group on 5th & 19th December with 28 people with diabetes. Whilst some people described excellent care and clear points of contact, when we asked 'What 3 aspects of your current diabetes care would you change to improve it?' the most popular responses were:

- More frequent appointments with more time to ask questions and checks such as footcare (9 responses)
- Better information and education, sometimes given varying advice (7 responses)
- Easier access and knowing who to approach to help with specific advice such as diet, feet (7 responses)

When asked what 3 aspects of your current diabetes care would you keep because it works well?

- Six monthly review (14 responses)
- Retinal screening and eye check (4 responses)
- Annual appt with consultant at NDDH
- GP contact (2 responses)
- A good practice nurse (2 responses)
- Diabetes group

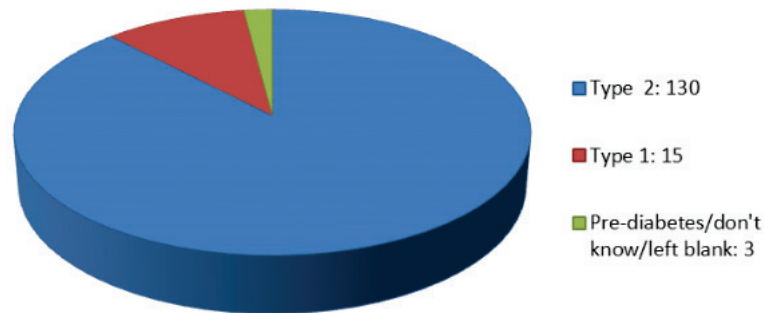
North Devon Integrated Diabetes Service Patient Engagement Report

Patient questionnaires

Questionnaires, based on the responses from the 22 patient interviews, were given to patients by practice nurses and diabetes specialist nurses during July and August 2017.

Type of diabetes

148 questionnaires were returned, the vast majority by people with Type 2 diabetes (see figure 1)



There were no discernible differences between the responses for Type 1 & Type 2 differences except in the answers to the following questions:

- In the last 3 months, has anything worried you about your diabetes:

8 out of 15 people with Type 1 diabetes said yes (53% had worries about diabetes in last 3 months)

89 out of 130 people with Type 2 diabetes said no (32% had worries about diabetes in last 3 months)

- In the last 3 months, have you ever been unsure about what to do with regard to your diabetes?

2 out of 15 people with Type 1 diabetes said yes (13% were unsure what to do in last 3 months)

95 out of 130 people with Type 2 diabetes said no (27% were unsure what to do in the last 3 months)

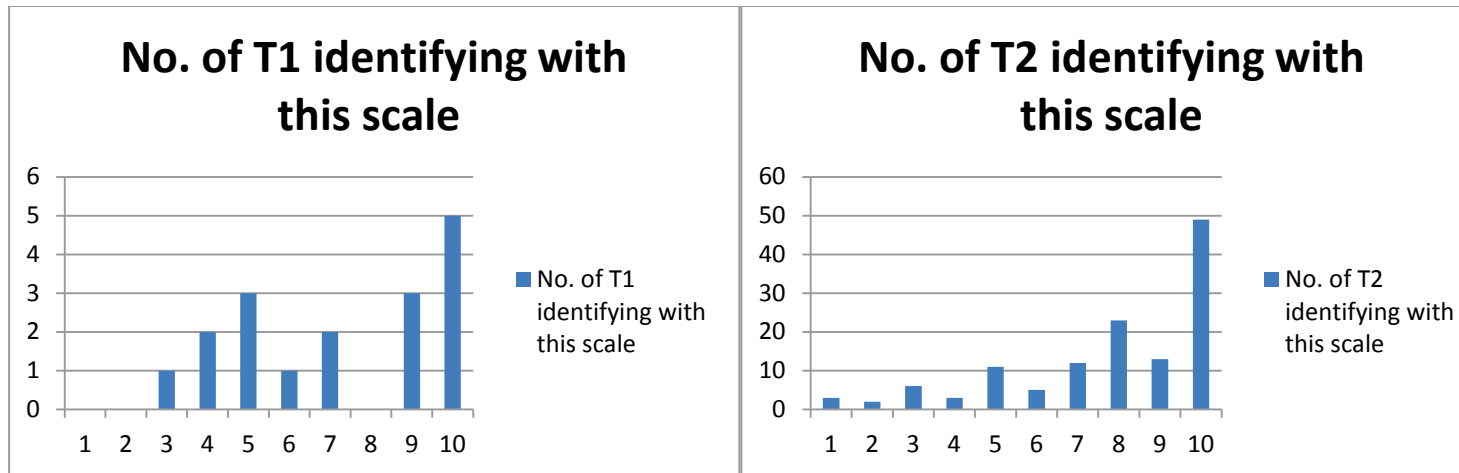
North Devon Integrated Diabetes Service Patient Engagement Report

The responses to the questions below have therefore not been split by the type of diabetes the person has.

Questions & Responses

Question 1

How easy is it for you to manage your health (score 1-10)?



Reasons given for score for Type 1 & Type 2 combined (as no discernible difference between the qualitative responses given):

Complications x 1

North Devon Integrated Diabetes Service Patient Engagement Report

Information x 2

“More help and details from diabetic nursing team – information”

“Because I understand what being diabetic means keep my levels low for long term better health”

Family x 2

“Problems with my partner who has been in hospital”

Self-management/lifestyle x 2

Specialists

- Continued access to specialist Doctor, Nurse and Dietician, I consistently fail to meet NICE guidelines H6A/c 48MMol/L BG level 5-7. Access to best technology.

Uncertainty

- Guesswork in how much insulin to take; Carb training (Dafne Course).

Diet/weight/exercise x 6

- **poor diabetic control, very over weight**

Struggle to understand food labelling

- **I have food issues ie comfort eat**

North Devon Integrated Diabetes Service Patient Engagement Report

Illness

- I am able to manage my diabetes well but sometimes my condition can be a little bit unstable if I feel poorly etc but this doesn't happen often, and I know how to deal with these situation; I feel I am in good health I eat well and exercise

Diabetes nurses

- Listening to diabetic nurses and do as they say eating sensibly.

Memory x 2

- To get a 10 it would take ... a good memory.

Other health conditions x 2

- **Vascular Dementia and Alzheimer's**

- **PMR & fibromyalgia, depression**

- - **Tired, depressed, change in diet**

Struggle with levels x 2

- **Unable to keep glucose levels low**

keeping sugar levels down despite reducing carbs

Lack of support x 1

North Devon Integrated Diabetes Service Patient Engagement Report

“Lack of support”

How <u>easy</u> is it for you to manage your health (score 1-10)?		
Score	Why?	What would it take for you to get to a 10?
0 No score		- Good control, lose weight
1		
2		- To be free of pain. - No sure.
3	- - -	- Partner to get better. - Weight loss possibly. - Happier in myself and more in control. - Sort my issues out
4	- Comfort eats due to pain	- Pain causes lack of exercise
5	- Too many things wrong brother helps	- To be better.

North Devon Integrated Diabetes Service Patient Engagement Report

	<ul style="list-style-type: none"> - Can't keep up with all the medication I am on - Because I like my food - Just started - Want to enjoy some pleasures in life occasionally - My own fault – self-inflicted – had for so long should know better! - Like my food too much - Can not what I like - Weight find it hard to loose weight and keep it off 	<ul style="list-style-type: none"> - Don't know. - Cut food intake. - Will power, clarity of information. - give up too many pleasures. - Determination and strong-will. - A miracle! - Anything or any help
6	<ul style="list-style-type: none"> - No additional comments - I watch my diet so I can delay needing drugs - Need to make low carb/sugar meals for 2. Husband a very hungry manual worker. Find meat & 2 veg very boring - Sometimes forget to take injections! -My weight is the biggest problem to control 	<ul style="list-style-type: none"> - Not have diabetes. - Supermarkets make it easier to identify low carb food. Then shopping wouldn't take so long. - Less busy life and taking my injections on time when I am out. - To be able to loose weight and to keep it off - To control it better

North Devon Integrated Diabetes Service Patient Engagement Report

<p>7</p>	<ul style="list-style-type: none"> - Weight control! 7/8 – Common sense/information/ encouragement from nurses & family - Having eaten what I wanted before my diabetes the willpower is weak at times not to e.g. chocolates, cake. - - Can get lead astray easily with regards to foods - Due to work effecting regular routine - Eating the right amounts and problem with knee and hip - I dislike dieting - I think I know how but not always got the motivation especially when tired. - Learnt to manage over the last 4 years - Tendency not to have regular meals Sleep pattern irregular 	<ul style="list-style-type: none"> - Weight loss. - knock off ten years?! - Will power. - To be perfect - Eating the right amount and exercising more - To stop liking food - Better self-esteem, somebody to share my feelings with when having down times - Don't know - Not have diabetes
<p>8</p>	<ul style="list-style-type: none"> - no comments left x4 - What my diet and do exercise - Not on medication. I avoid foods high in sugar (>2 to 4%). These are not always easy to find 	<ul style="list-style-type: none"> - Change my attitude to what I eat. I eat for enjoyment. - Breakfast cereals are nearly all too sweet. I have to keep off wine, as these never show sugar content, only alcohol content. It would be nice to have, say, one glass a week!

North Devon Integrated Diabetes Service Patient Engagement Report

<ul style="list-style-type: none"> - A combination of 'healthy eating' and taking metformin - Education on Diet etc - Twice daily blood tests and injections - I follow according to medical guidelines to manage my condition - Getting older, worried about wife - Can't resist sweet things - Need to lose more weight and eat less fat!! - Still sorting diet. - Have reduced quantity of food over last 12 months have ticked 8 due to obvious ageing of my body! - Packaging! Always having to double check sugars! - Have lost weight - Exercise dogs try to eat well 	<ul style="list-style-type: none"> - More exercise and no relapses from 'healthy eating'. - There will always be things that get in your way. - Not possible unless alternative treatment available. - Keep at it – to stay healthy and fit. - Probably nothing. - Lose weight. - Good diet. - ?Possibly losing the extra weight and not eating as much cream cheese which I love! Plus fruit!! - Possibly more frequent podiatry checks and circulation checks - Probably more strict with diet - No problem with my feet - More weight loss - Manage weight and stress a little better - Breakfast cereals are nearly all too sweet. I have to keep off wine, as these never show sugar content, only alcohol content. It would be nice to have ,
--	---

North Devon Integrated Diabetes Service Patient Engagement Report

	<ul style="list-style-type: none"> - not on medication. I avoid foods high in sugar (>2 to 4%) These are not always easy to find - a combination of 'healthy eating' and taking metformin 	<p>say, one glass a week!</p> <ul style="list-style-type: none"> - More exercise and no relapses from 'healthy eating' -- don't eat?
9	<ul style="list-style-type: none"> - No additional comments given – x4 - Take less tablets! - Remembering tablets etc - Lose weight. - Routine and medication easy to follow. - I know what I should/should not eat and drink - Problem keeping weight off - I do my best to eat healthy and exercise 	<ul style="list-style-type: none"> - A little more self-discipline. - More willpower! - Lose weight - Down to my willpower I think - Exercise more
10	<ul style="list-style-type: none"> - no additional comments given – x28 - Have a little sugar as possible in all meals, no snacks, diet soft drinks. - I don't think about it. 	

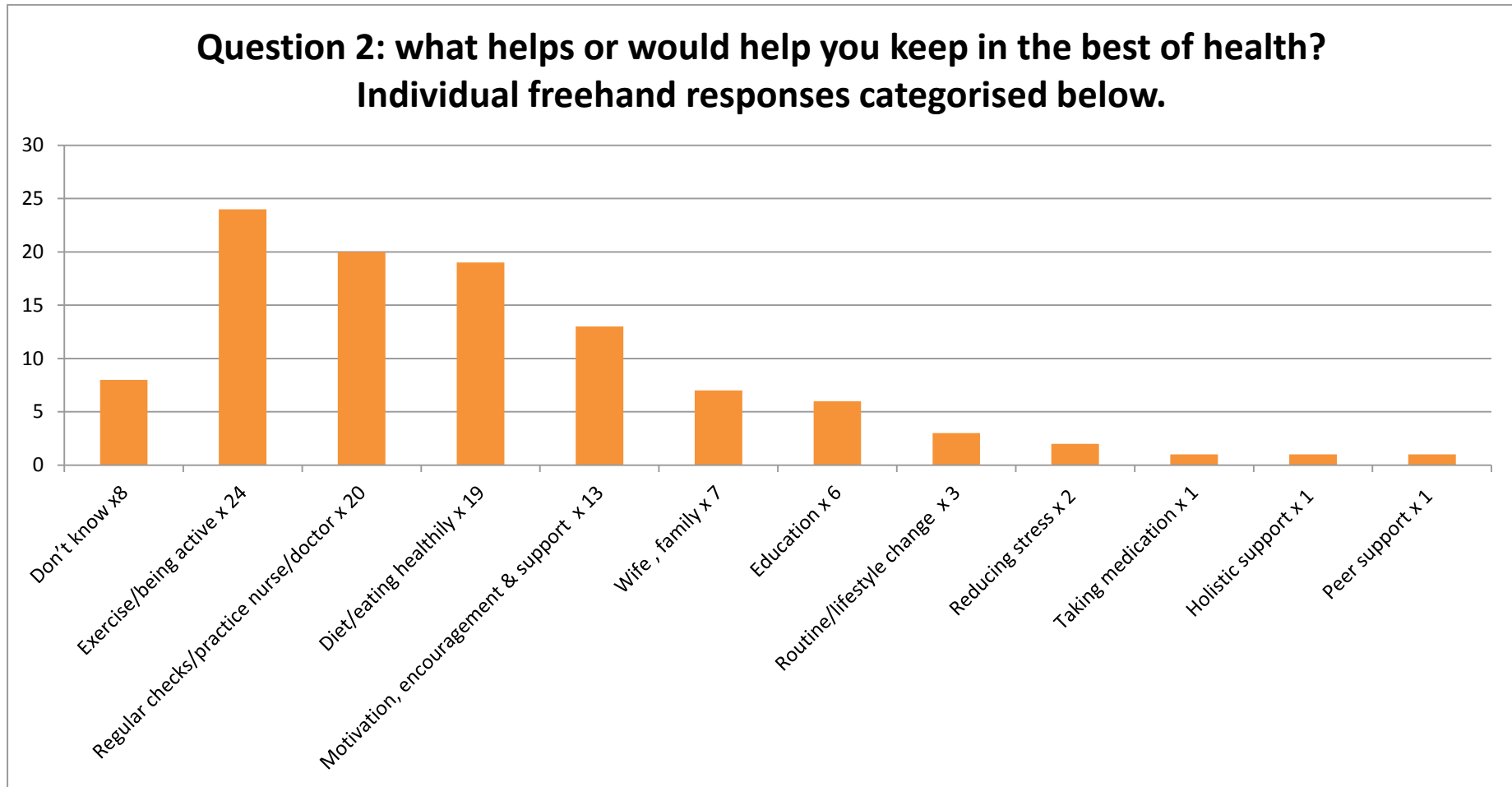
North Devon Integrated Diabetes Service Patient Engagement Report

	<ul style="list-style-type: none">-- With the help of my wife.- I have had diabetes for 17 years, during this time I have made every effort to keep myself as well as I can- I am used to the restrictions as a family history.- Well looked after – doctor & family.- No problems (x2)- Feel that I am there-Because I live with a partner who encourages me to take care of my health & is quite happy to adapt to my diet if requested.- Family help- Good support- All I have to do is take the prescribed tablets regularly	

North Devon Integrated Diabetes Service Patient Engagement Report

Question 2

What helps or would help you keep in the best of health?



North Devon Integrated Diabetes Service Patient Engagement Report

These are some of the comments that were provided in answer to Question 2:

Diet/eating healthily x 19

Lose weight (not easy)

Diet would make me feel better no picking in-between meals

Advice about diet

List of foods should and shouldn't eat

Not to feel hungry all the time

Still waiting for hospital to contact me regarding appointment to go through diets etc. and info about Diabetes (over a year waiting)

A good cook

Feet hard skin suffer a lot from weight. Losing fat around stomach area finding it very hard and upsetting.

Regular meals not too much sweet stuff.

Exercise/being active (x 24)

As long as I am fit enough to get exercise should do the trick.

More exercise once knee better.

Need to walk more.

Stay as active and 'normal' as possible

North Devon Integrated Diabetes Service Patient Engagement Report

Giving myself more time to exercise more

More movement, but difficult due to pain

Motivation, encouragement & support x 13

Perhaps a fitness type coach

Need plenty of support and bullying

Having more will power than a goldfish.

I think more threats, pictures of bits being removed due to the illness would help, a bit more shock and awe!

Support and help to meet the NICE target.

Practice checks x 20

I appreciate the twice-a-year check-up.

Have several appointments at clinic monitoring all health issues.

An annual review in my birthday month.

I am reviewed every 6 months by (practice nurse) If I have any queries, I feel I can discuss them with her.

I am quite competitive and need to 'beat' my previous readings.

More foot checks

Having more people like (practice nurse). Best care I have ever received.

Help with stress x 2

North Devon Integrated Diabetes Service Patient Engagement Report

To be able to be stress free so I can concentrate on my health

Relaxation techniques

Routine/lifestyle change x 3

Less busy life.

Routine that fits with lifestyle. Plus lifestyle changes.

Holistic support x 1

Having support from knowledgeable staff who understand the whole 'me' and my health issues. Not just pat answers.

Education/information x 6

Visits from diabetic teams in schools and colleges i.e. knowledge in early life.

Being able to access information quickly, either through a book or being able someone to speak to

Daphne course.

Peer support x 1

Share experience with other similar people. Not get too hung up on where I am. To know where I am on the scale.

Wife , family x 7

My wife and with her pushing me more.

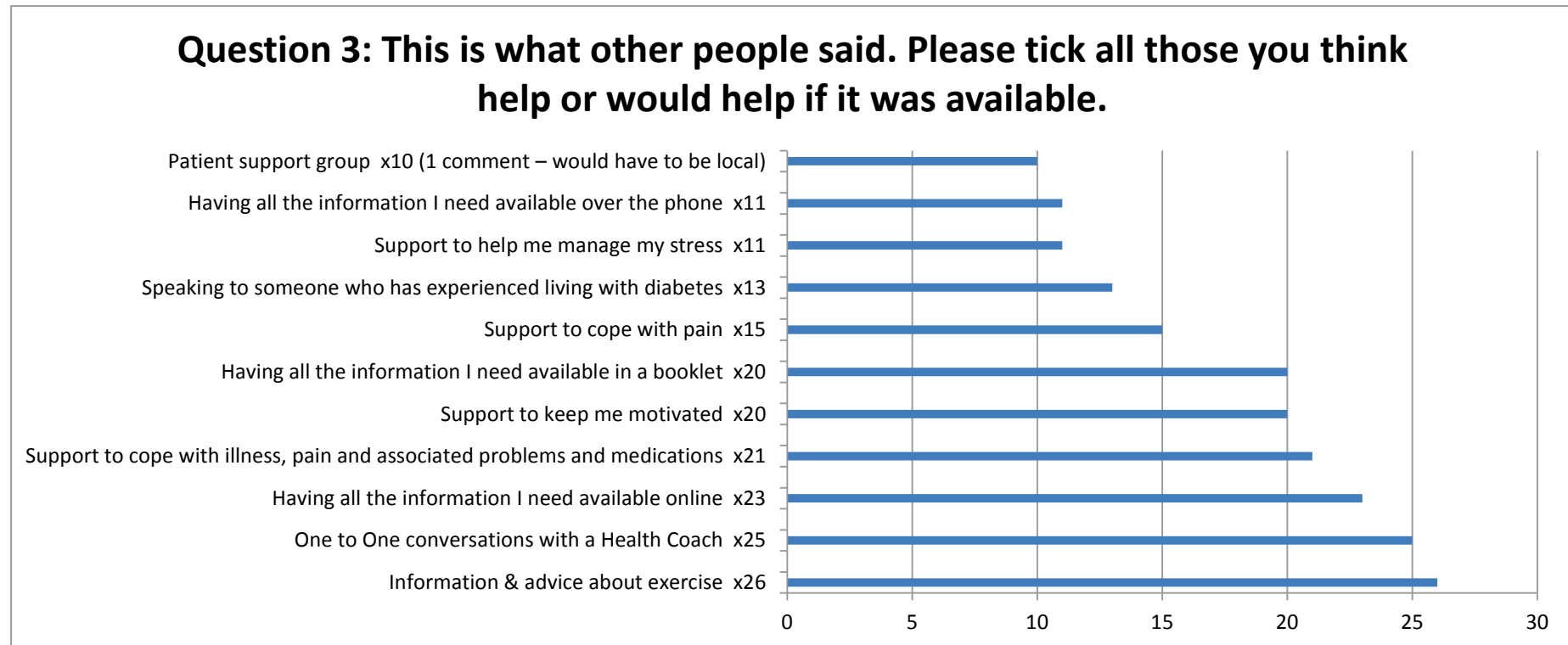
Family and friends keeping me in check.

A partner who would exercise or go walking with me

North Devon Integrated Diabetes Service Patient Engagement Report

Question 3

This is what other people said. Please tick all those you think help or would help if it was available.



North Devon Integrated Diabetes Service Patient Engagement Report

Other conditions x 3 (more what makes it hard)

I don't think that I can get any healthier given my underlying condition of auto-immune hepatitis.

To not have the conditions I have to enable me to be more active

not a lot more can help with multiple health problems