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Jindal-Snape, Divya; Keiller, Andrew ; Kelly, Lynn; Langlands-Scott, Judith; Murray, Christopher; Snape, Anj

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FIBROMYALGIA

AND US

LIVING WITH FIBROMYALGIA

FIBROMYALGIA AND US

A PAIN CLINIC PSYCHOLOGIST RECENTLY SAID TO ME THAT MORE NEEDS TO BE DONE TO RAISE THE AWARENESS OF HEALTH CARE PROFESSIONALS ABOUT FIBROMYALGIA. WITH SOME PROGRESS IN RESEARCH, THERE IS A BETTER UNDERSTANDING OF FIBROMYALGIA COMPARED TO WHAT IT WAS EVEN TWO YEARS AGO. HOWEVER, WHETHER YOUR OWN DOCTOR, PHYSIOTHERAPIST OR OTHER PROFESSIONALS UNDERSTAND THIS COMPLEX CONDITION, STILL FEELS LIKE A LOTTERY. SO ONE DAY LYING IN BED, WITH A FIBROMYALGIA FLARE UP, I STARTED THINKING OF CREATING A COMIC ABOUT IT. I FIRED OFF EMAILS TO A FEW PEOPLE WHO ALL THANKFULLY CAME ON BOARD.

THIS COMIC HAS BEEN DESIGNED WITH THE PURPOSE OF RAISING AWARENESS OF FIBROMYALGIA AMONGST PROFESSIONALS, FAMILIES, AND COMMUNITIES. IT ILLUSTRATES THE ONGOING LIFE TRANSITIONS OF THOSE WHO HAVE FIBROMYALGIA AS WELL AS ITS IMPACT ON SIGNIFICANT OTHERS. IT HIGHLIGHTS THE IMPORTANCE OF A STRONG SUPPORT NETWORK TO ENABLE PEOPLE TO ADAPT TO THE MULTIPLE TRANSITIONS TRIGGERED BY FIBROMYALGIA AND FLOURISH DESPITE ITS SUBSTANTIAL CHALLENGING CONSEQUENCES.

I AM REALLY GRATEFUL TO ALL THE CONTRIBUTORS, SCRIPT WRITERS, ARTISTS AND PROFESSOR CHRIS MURRAY FOR SUPPORTING ME IN TURNING THIS IDEA INTO REALITY.

DIVYA JINDAL-SNAPE

DIRECTOR, TRANSFORMATIVE CHANGE: EDUCATIONAL AND LIFE TRANSITIONS (TCELT) RESEARCH CENTRE
UNIVERSITY OF DUNDEE

D.JINDALSNAPE@DUNDEE.AC.UK

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SCRIPT: LYNN KELLY, **ART:** LETTY WILSON

WITH THANKS TO DAVID ROBERTSON

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FRONT COVER BY ASHLING LARKIN AND REBECCA HORNER. BACK COVER BY HELEN ROBINSON.

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LIVING AND WORKING WITH FIBROMYALGIA

DR. X TO THE RESCUE!

I NOW HAVE A GP WHO IS VERY KNOWLEDGEABLE AND SEEMS TO HAVE READ EVERY RESEARCH PAPER ON FIBROMYALGIA!

6 YEARS AFTER MY DIAGNOSIS I FOUND OUT IT'S NOT ALL IN MY HEAD.

IT'S SUCH A NOVELTY TO HAVE SOMEONE WHO KNOWS SO MUCH ABOUT FIBROMYALGIA.

AS SOON AS SOME NEW RESEARCH COMES OUT HE CONSIDERS OTHER OPTIONS,

LIKE GETTING ME TESTED FOR VITAMIN D DEFICIENCY AS SOME OF THE SYMPTOMS ARE SIMILAR.

MOST IMPORTANTLY, HE TREATS ME AS A EDUCATED PERSON WITH THE RIGHT TO KNOW ANYTHING WORTH KNOWING ABOUT MY CONDITION.

HE TAKES AN INTEREST IN MY WORK AND UNDERSTANDS WHY I CAN'T TAKE MEDICATION REGULARLY AND WHY I WORK LONG HOURS.

HE SEES ME AS A PERSON AND NOT A CONDITION.

THERE MAY NOT BE A CURE AT THE MOMENT,

BUT INFORMED DOCTORS, AN UNDERSTANDING AND LOVING FAMILY, FRIENDS AND COLLEAGUES MAKE A BIG DIFFERENCE.

FIBROMYALGIA DOES NOT DEFINE ME. I HAVE FIBROMYALGIA BUT IT IS A TINY PART OF MY LIFE... OF WHO I AM!

THE MASK

I FEEL ANNOYED
AT MYSELF FOR IGNORING
THE INDICATORS OF STRESS
AND INACTIVITY
FOR YEARS.

I USED TO WORK
AND PLAY BUT NEVER
EXERCISE AND MY DIET
WAS POOR - FAR TOO MUCH
OVER COMPENSATING FOR
FEELING RUBBISH.

I WISH PEOPLE
WOULD LOOK AFTER
THEMSELVES BETTER AND NOT
WORK SO MUCH.

THERE IS
MUCH MORE TO LIFE
THAN WORK AND I DON'T
WANT TO RETIRE WITH
A GOOD CV BUT NOT
ABLE TO ENJOY THE
NEXT CHAPTER
OF MY LIFE.

MISDIAGNOSED

WHERE HAS SHE FALLEN ASLEEP THIS TIME?
THE TIDE IS COMING IN!

SHE'S OVER HERE! ASLEEP AGAIN...

I'D FALL ASLEEP ALL THE TIME. I FELT LIKE I WAS MISSING OUT ON MY CHILDHOOD.

YIKES! HOW DO YOU DO IT JUDITH?

HOW DO YOU DO IT, JUDITH?
YOU'VE DISLOCATED YOUR KNEE.
LAST TIME IT WAS YOUR WRIST;
THE TIME BEFORE IT WAS YOUR ANKLE...

BOOKS. I WAS CARRYING A BAG
OF BOOKS AND THIS HAPPENED.

BUT YOU ARE SO CLEVER. YOU SHOULD BE HEADING TO UNIVERSITY,
YOU SHOULD BE CARVING OUT A HIGH-FLYING CAREER! THIS ISN'T NORMAL.

I KNOW, IT MUST BE SO TERRIBLE FOR YOU...

FAT LOT OF GOOD THIS IS DOING!

I HAVE THE ANSWER - YOU HAVE
FIBROMYALGIA.

FIBRO-MY-WHO-WHAT?
CAN YOU CURE THAT?

HAHAHAHAHAHA!

OH *AHEM*, UMM, NO. WE PREFER
THE TERM 'MANAGE'.

NOW, FIBROMYALGIA DOES NOT CAUSE
PHYSICAL INJURY, JUST PAIN. SO JUST
PUSH ON THROUGH THE PAIN, YOU WILL
BE PERFECTLY FINE.

OH, I CAN DO THAT, SURE!

HEY, WHY DO YOU NEVER TURN UP TO ANYTHING? WE NEVER SEE YOU ANYMORE AND YOU NEVER DO ANYTHING!

I HAVE FIBROMYALGIA.

ISN'T THAT PSYCHOSOMATIC? LIKE, YOU THINK YOU'RE GOING TO BE ILL SO YOU GET ILL?

NO. NO IT IS NOT.

I AM NOW CONVINCED THAT YOUR BOY HAS EHLERS DANLOS HYPERMOBILITY DUE TO THE FACT HE IS FLOPPY AND HIS JOINTS ARE LAX. EHLERS DANLOS HYPERMOBILITY IS GENETIC WHICH MEANS...

FIBROMYALGIA

BLAH, BLAH, BLAH...

EHLERS
DANLOS

FINALLY I GOT THE RIGHT DIAGNOSIS FOR MY FATIGUE, PAIN, HYPERMOBILE JOINTS AND REPEATED INJURIES.

UNFORTUNATELY, THE YEARS OF "PUSHING THROUGH THE PAIN", AS I'D BEEN ADVISED TO DO, HAD TAKEN THE TOLL ON MY BODY. THE PAIN WAS DUE TO PHYSICAL INJURY.

I NOW HAVE TO FACE SPENDING MUCH OF MY TIME IN A WHEELCHAIR OR ON CRUTCHES DUE TO MY DAMAGED LIGAMENTS AND TENDONS.

EHLERS-DANLOS SUFFERERS OFTEN GO ON TO DEVELOP SECONDARY FIBROMYALGIA, BUT THE FIBRO DIAGNOSIS BLINDED DOCTORS AND THEY FAILED TO SEE THE UNDERLYING CONDITION.

IT ALSO MEANS HARD TIMES AHEAD FOR MY SON WHO WILL HAVE TO USE A WHEELCHAIR, FROM TIME TO TIME, TO LIMIT PAIN AND INJURY.

IN MY CASE, THE RIGHT ADVICE FOR THE WRONG DIAGNOSIS PROVED TO BE WORSE THAN NO ADVICE AT ALL.

WE GET THROUGH IT.

AM I ANGRY THAT DOCTORS ALL TOO READILY IGNORED MY SYMPTOMS AND HUNG EVERYTHING ON FIBRO? I CHOOSE NOT TO BE... I DON'T HAVE THE TIME.

TAKING CONTROL OF FIBRO

WHAT IS FIBROMYALGIA? A DOCTOR'S PERSPECTIVE

"REVIEW PAIN LEVELS A COUPLE OF MONTHS INTO A TREATMENT AND IF THE PAIN IS THE SAME AS PRE-TREATMENT CONSIDER STOPPING."

"THIS WILL AVOID A PATTERN OF CONTINUOUS ADDITION OF MEDICATION WITH NO IMPROVEMENT IN OVERALL PAIN LEVELS, WITH ALL THE SIDE EFFECTS THAT COME WITH THIS."

"ENCOURAGE GRADED EXERCISE PROGRAMMES, AVOID 'BOOM AND BUST' STRATEGIES."

TREAT CONCURRENT AND POSSIBLY CONTRIBUTING FACTORS, FOR EXAMPLE, VITAMIN D DEFICIENCY AND DEPRESSION.

"EXPLORE SENSITIVELY ANY TRAUMATIC EVENTS THAT MAY CONTRIBUTE TO PAIN. NO ONE FULLY UNDERSTANDS FIBROMYALGIA OR OTHER PAIN SYNDROMES. LEVELS OF TRAUMA ARE VARIABLY REPORTED IN RESEARCH. THIS ISN'T THE WHOLE STORY BUT IT IS WORTH CONSIDERING - AT THE RIGHT TIME - IN INDIVIDUAL PATIENTS."

KEEPING THESE IN MIND WILL MAKE A **HUGE DIFFERENCE** TO PATIENTS WHO HAVE FIBROMYALGIA.

ADVICE FROM A PHYSIOTHERAPIST

EXERCISE GUIDED BY A PHYSIOTHERAPIST CAN PLAY A CRUCIAL ROLE IN HELPING PATIENTS MANAGE THEIR FIBROMYALGIA. IT IS IMPORTANT THOUGH TO GET ADVICE AND GUIDANCE IF YOU ARE NOT SURE WHERE TO START.

"SOME PEOPLE CAN FIND EXERCISING A REAL CHALLENGE, AND YET YOUR BODY IS DESIGNED TO MOVE, SO FINDING THE RIGHT LEVEL OF EXERCISE, AND HOW AND WHEN TO PROGRESS IT CAN BE ENORMOUSLY BENEFICIAL."

"A PHYSIOTHERAPIST WITH AN INTEREST IN FIBROMYALGIA CAN BE A GREAT HELP. EXERCISING IN A HYDROTHERAPY POOL CAN BE A GREAT PLACE TO START."

"UNDERSTANDING THE EFFECTS, SENSATIONS AND PAINS THAT CAN BE EXPERIENCED WHEN STARTING AN EXERCISE PROGRAMME IS REALLY IMPORTANT. THIS IS WHERE A PHYSIOTHERAPIST CAN HELP WITH SOME SUPPORT AND ANSWERS."

FIBROMYALGIA: THE FACTS

FIBROMYALGIA IS A CHRONIC HEALTH PROBLEM THAT CAUSES PAIN ALL OVER THE BODY AND OTHER SYMPTOMS. IT AFFECTS TWO TO FOUR PERCENT OF PEOPLE, WOMEN MORE OFTEN THAN MEN.

DIAGNOSIS

DIAGNOSIS CAN TAKE A LONG TIME AS SYMPTOMS OF FIBROMYALGIA VARY AND CAN BE SIMILAR TO OTHER CONDITIONS, SUCH AS RHEUMATOID ARTHRITIS OR CHRONIC FATIGUE SYNDROME. CRITERIA FOR DIAGNOSIS THESE DAYS ARE BASED ON THE TOTAL NUMBER OF PAINFUL AREAS, AND LEVEL OF SEVERITY OF:

- FATIGUE
 - WAKING UNREFRESHED
 - COGNITIVE PROBLEMS
- SYMPTOMS HAVE STAYED UNCHANGED FOR AT LEAST THREE MONTHS, AND NO OTHER REASON FOR THE SYMPTOMS WAS FOUND

MAIN SYMPTOMS:

- TENDERNESS TO TOUCH
- SEVERE FATIGUE
- SLEEP DISTURBANCE
- PROBLEMS WITH MEMORY OR THINKING CLEARLY

CAUSES OF FIBROMYALGIA

THIS IS NOT CLEAR BUT A NUMBER OF FACTORS MIGHT BE INVOLVED:

ABNORMAL PAIN MESSAGES MIGHT BE DUE TO CHANGES IN THE WAY THE CENTRAL NERVOUS SYSTEM PROCESSES THE PAIN MESSAGES CARRIED AROUND THE BODY

SLEEP PROBLEMS MAY BE A CAUSE RATHER THAN A SYMPTOM

CHEMICAL IMBALANCES SUCH AS ABNORMALLY LOW LEVELS OF THE HORMONES SEROTONIN, NORADRENALINE AND DOPAMINE IN THE BRAIN MAY BE A FACTOR

GENETICS MAY PLAY A SMALL PART WITH SOME PEOPLE PERHAPS MORE LIKELY THAN OTHERS TO DEVELOP THE CONDITION

POSSIBLE TRIGGERS

IT IS SUGGESTED THAT FIBROMYALGIA IS TRIGGERED BY A PHYSICAL OR EMOTIONAL TRAUMA, E.G.,

- INJURY
- SURGERY
- A VIRAL INFECTION
- ABUSIVE RELATIONSHIP
- SIGNIFICANT BEREAVEMENT

HOWEVER, AT TIMES, NO OBVIOUS TRIGGERS ARE PRESENT.

TREATMENT

THERE IS NO KNOWN CURE AT PRESENT. AS IT HAS NUMEROUS SYMPTOMS, IT DOES NOT HAVE A SINGLE TREATMENT. THERE ARE SEVERAL TREATMENTS OFFERED IN COMBINATION SUCH AS:

- PAIN KILLERS
- MUSCLE RELAXANTS
- HYDROTHERAPY
- PHYSICAL EXERCISE
- COGNITIVE BEHAVIOURAL THERAPY (CBT)
- ALTERNATIVE THERAPIES, SUCH AS MASSAGE AND ACUPUNCTURE

YOUR GP WILL PLAY A CENTRAL ROLE IN FINDING THE BEST TREATMENT FOR YOU.

Source: American College of Rheumatology

<http://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Fibromyalgia>

USEFUL WEBSITES

UK Fibromyalgia

<http://ukfibromyalgia.com/>

American College of Rheumatology

<http://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Fibromyalgia>

National Fibromyalgia Association

<http://www.fmaware.org/>

Fibromyalgia Action UK

<http://www.fmauk.org>

PROCESS WORK

THUMBNAIL

LAYOUT

INKS

tone

LIVING AND WORKING WITH FIBROMYALGIA - THUMBNAILS

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FRONT COVER - INKS (ASHLING LARKIN)

COLOUR (REBECCA HORNER)

CONTRIBUTOR BIOS

PROFESSOR DIVYA JINDAL-SNAPE IS CHAIR OF EDUCATION, INCLUSION AND LIFE TRANSITIONS; AND ASSOCIATE DEAN (RESEARCH) IN THE SCHOOL OF EDUCATION AND SOCIAL WORK, UNIVERSITY OF DUNDEE. SHE IS ALSO DIRECTOR OF THE TRANSFORMATIVE CHANGE: EDUCATIONAL AND LIFE TRANSITIONS (TCELT) RESEARCH CENTRE. SHE HAS HAD CHRONIC PAIN SINCE THE AGE OF 17, BUT IT WAS NOT DIAGNOSED AS FIBROMYALGIA UNTIL SHE WAS 40. **DR. JONATHAN SNAPE**, DIVYA'S HUSBAND, AND THEIR CHILDREN, **NIK AND ANJ**, CONTRIBUTED TO THE DEVELOPMENT OF HER STORY. DR SNAPE IS HEAD OF JAMES HUTTON LIMITED, INVERGOWRIE. NIK AND ANJ ARE AT SECONDARY SCHOOL AND ENJOY SPORTS, MUSIC, AND DRAMA.

ASHLING LARKIN IS AN ILLUSTRATOR, COMIC ARTIST AND ANIMATOR BASED IN DUNDEE. SHE CURRENTLY WORKS AS A WORKSHOP FACILITATOR AT THE DUNDEE COMICS CREATIVE SPACE, IS A RESIDENT ARTIST AT INK POT STUDIO, AND IS THE ART DIRECTOR FOR *FEARLESS FEMME*, A WEB MAGAZINE.

DR. LYNN KELLY IS A SENIOR LECTURER IN THE SCHOOL OF EDUCATION AND SOCIAL WORK AND PROGRAMME DIRECTOR FOR THE MSC LEADERSHIP AND INNOVATION. LYNN IS ALSO A MEMBER OF THE PAROLE BOARD FOR SCOTLAND. RESEARCH AREAS INCLUDE CHILD PROTECTION, PROFESSIONAL LEARNING AND HIGH RISK OFFENDERS. LYNN IS ALSO AN ENTHUSIASTIC IF NOT PARTICULARLY ACCOMPLISHED GYM GOER AND CREDITS THE SUPPORT SHE HAS HAD FROM HER FAMILY AND THE INSTITUTE OF SPORT AND EXERCISE AT THE UNIVERSITY OF DUNDEE AND HER EQUALLY ENTHUSIASTIC 'GYM BUDDY', WITH HER CONTINUED STRENGTH AND WELL-BEING.

LETTY WILSON IS THE ARTIST ON AWARD-WINNING SCI-FI SERIES *COSMIC*, WRITTEN BY ERIN KEEPERS. SHE HAS CONTRIBUTED TO VARIOUS ANTHOLOGIES AND HAS SEVERAL OTHER BOOKS PUBLISHED WITH *PANELS*, A COLLABORATIVE GROUP BASED IN GLASGOW, SCOTLAND, INCLUDING THE SICBA AWARD-WINNING GRAPHIC NOVEL *A STRANGER CAME TO TOWN*.

JUDITH LANGLANDS-SCOTT IS A SELF-RESCUING PRINCESS BIBLIOPHILE WITH A WILL OF IRON AND A HEART OF GOLD. TEMPERED BY YEARS OF SOCIAL AND MEDICAL DISBELIEF IN THE VALIDITY OF HER AND HER CHILDREN'S EDS AND AUTISTIC SYMPTOMS, SHE IS A PASSIONATE ADVOCATE FOR BOTH. SHE'S BENDY, BUT UNBROKEN.

ZU DOMINIAK SPENDS MOST OF THE TIME DRAWING COMICS. YOU CAN FIND THEM HERE: WWW.ZYZANNA.COM

ANDREW KEILLER IS PASSIONATE ABOUT COMICS. HE WAS DIAGNOSED WITH FIBROMYALGIA WHEN HE WAS 14.

ELLIOT BALSON IS A DUNDEE-BASED COMIC ARTIST. HIS WORK CAN BE FOUND IN VARIOUS UNIVERSE PUBLICATIONS, *COMICHAUS*, AND AN UPCOMING ANTHOLOGY CALLED *MASKS*. HE IS CURRENTLY WORKING ON HIS OWN SERIES, *UNTETHERED*, WITH WRITER UMAR DITTA.

PROFESSOR CHRIS MURRAY IS CHAIR OF COMICS STUDIES AT THE SCHOOL OF HUMANITIES, UNIVERSITY OF DUNDEE. HE IS ASSOCIATE DEAN FOR KNOWLEDGE EXCHANGE AND PARTNERSHIPS, LEADS THE MLITT IN COMICS AND GRAPHIC NOVELS COURSE, AND IS DIRECTOR OF THE SCOTTISH CENTRE FOR COMICS STUDIES AND DUNDEE COMICS CREATIVE SPACE. HE HAS PUBLISHED ON THE BRITISH SUPERHERO, ALAN MOORE AND GRANT MORRISON, HORROR COMICS, COMICS AND LITERATURE, AND COMICS AND PROPAGANDA. HE IS CO-EDITOR OF *STUDIES IN COMICS* (INTELLECT) AND UNIVERSE COMICS, AND CO-ORGANISER OF THE INTERNATIONAL COMICS AND GRAPHIC NOVELS CONFERENCE.

DR. BRYAN WHITTINGHAM GRADUATED IN 2000 FROM UNIVERSITY OF GLASGOW AND IS A GP IN DUNDEE.

DR. DAMON HERD IS THE COORDINATOR OF THE DUNDEE COMICS CREATIVE SPACE. HE IS ALSO AN ARTIST AND RESEARCHER WITH A PHD IN COMICS FROM THE UNIVERSITY OF DUNDEE. HIS RESEARCH AREA IS AUTOBIOGRAPHICAL COMICS, PERFORMANCE, AND THE GAMES AUTHORS PLAY WITH TRUTH. HE IS THE FOUNDER AND ORGANISER OF *DEECAP* (DUNDEE COMICS/ART/PERFORMANCE). FOLLOW HIM ON TWITTER @TICKINGBOY

FREDDIE WARDEN IS A SENIOR OUTPATIENT PHYSIOTHERAPIST AT KINGS CROSS, DUNDEE. HE HAS AN INTEREST IN MANAGING AND HELPING PEOPLE UNDERSTAND PERSISTENT PAIN.

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FIBROMYALGIA IS A CONDITION ASSOCIATED WITH CHRONIC PAIN AND FATIGUE, ALONG WITH SEVERAL OTHER SYMPTOMS. ITS CAUSES AND TREATMENT ARE NOT FULLY UNDERSTOOD.

THIS COMIC BRINGS TOGETHER STORIES OF PEOPLE LIVING WITH FIBROMYALGIA, AS WELL AS PERSPECTIVES OF THOSE SUPPORTING THEM.

DISCOVER WHAT IT IS LIKE TO LIVE WITH FIBROMYALGIA, NOT JUST AS AN INDIVIDUAL, BUT AS A FAMILY

LEARN ABOUT THE PRESSURES OF LIVING AND WORKING WITH FIBROMYALGIA

CONSIDER THE CONSEQUENCES OF A MISDIAGNOSIS OF FIBROMYALGIA

LEARN HOW FIBROMYALGIA CAN IMPACT CHILDREN

SEE A DOCTOR EDUCATE MEDICAL STUDENTS ABOUT THE CONDITION

GET ADVICE FROM A PHYSIOTHERAPIST ON HOW TO COPE WITH FIBROMYALGIA