Table 1 SF-36 scores for adults with CMT and comparative Australian norms, and sub-grouped for gender and age.

Sample (N)	Physical Function	Role Physical	Bodily Pain	General Health	Vitality	Social Function	Role Emotional	Mental Health
Australian Norms (N=18,800)	82.5 (23.9)	79.8 (35.1)	76.8 (25.0)	71.6 (20.3)	64.5 (19.8)	84.9 (22.5)	82.8 (32.3)	75.9 (17.0)
Total CMT sample (N=295)	54.9 (28.4)*	60.5 (41.5)*	64.9 (25.3)*	61.4 (23.5)*	50.5 (21.7)*	76.8 (25.4)*	75.9 (37.5)*	72.3 (18.1)*
Gender								
- Men (N=124)	54.6 (29.2)	59.6 (40.6)	65.0 (27.7)	60.2 (24.1)	51.5 (21.3)	76.0 (27.6)	75.1 (38.3)	72.2 (19.1)
- Women (N=171)	55.1 (27.9)	61.2 (42.3)	64.9 (23.5)	62.2 (23.1)	49.7 (22.0)	77.4 (23.8)	76.6 (36.9)	72.3 (17.4)
Age								
- 18 to 24 years (N=22)	59.8 (27.7)	65.9 (39.0)	65.9 (21.1)	67.3 (22.1)	52.5 (16.4)	79.5 (20.2)	77.3 (36.2)	68.5 (18.4)
- 25 to 34 years (N=46)	69.5 (24.9)	71.7 (36.7)	68.0 (22.8)	63.2 (25.2)	52.9 (21.3)	79.5 (24.0)	76.8 (37.1)	69.6 (19.4)
- 35 to 44 years (N=51)	58.4 (25.0)	66.2 (40.8)	64.3 (25.2)	60.9 (21.2)	51.4 (20.4)	79.2 (23.3)	81.7 (34.2)	73.0 (15.7)
- 45 to 54 years (N=54)	62.3 (26.6)	67.1 (42.6)	66.0 (25.1)	61.0 (23.3)	52.2 (24.1)	78.0 (25.6)	77.8 (36.6)	71.6 (17.4)
- 55 to 64 years (N=60)	45.2 (26.5)#	56.7 (39.8)	65.1 (27.4)	61.3 (25.8)	46.6 (24.0)	77.5 (25.6)	76.7 (37.0)	74.5 (19.2)
- 65 to 74 years (N=43)	51.4 (28.0)⬩	47.7 (42.9)	64.0 (28.5)	60.4 (22.0)	50.2 (20.4)	73.8 (24.8)	65.9 (43.9)	71.0 (17.9)
- 75 + years (N=19)	21.8 (22.4)†	34.2 (42.7)#	57.2 (24.6)	55.1 (24.5)	47.5 (20.2)	62.5 (36.1)	71.9 (37.3)	79.8 (18.3)

Values are mean (SD). *Significant difference compared to Australian norms ($P<0.01$); † Significantly lower than all other age groups ($P<0.05$); # Significantly lower than those aged 25-34 years and 45-54 years ($P<0.05$); ⬩ Significantly lower than those aged 25-34 years ($P<0.05$).

Note: SF-36 scored 0-100 in each dimension, where 0 represents extremely poor health and 100 is perfect health. Physical dimensions: physical functioning, impact of physical health on role performance (role physical), bodily pain, general health. Mental dimensions: vitality, social functioning, impact of emotional health on role performance (role emotional), general mental health.

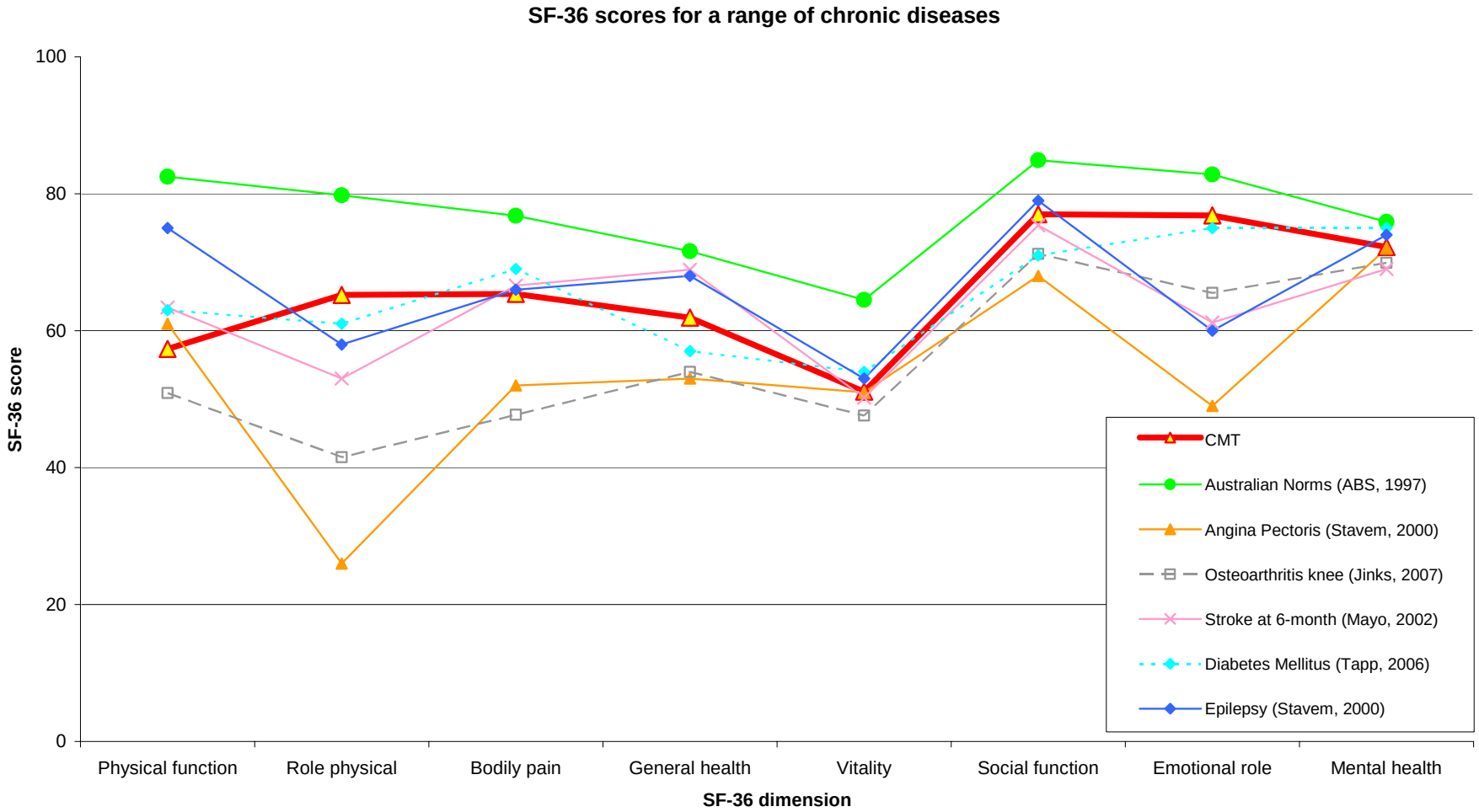
SF-36 scores for a range of chronic diseases
SF-36 score
100
80
60
40
20
0
Physical function
Role physical
Bodily pain
General health
Vitality
Social function
Emotional role
Mental health
SF-36 dimension
CMT
Australian Norms (ABS, 1997)
Angina Pectoris (Stavem, 2000)
Osteoarthritis knee (Jinks, 2007)
Stroke at 6-month (Mayo, 2002)
Diabetes Mellitus (Tapp, 2006)
Epilepsy (Stavem, 2000)

Table 2 Logistic regression modelling for predictors of SF-36 dimensions in CMT.

Predictors	Physical Function	Role Physical	Bodily Pain	General Health	Vitality	Social Function	Role Emotional	Mental Health
Age	1.82* (1.37-2.43)	1.38* (1.07-1.79)	0.89 (0.69-1.14)	0.87 (0.68-1.12)	1.28 (0.99-1.64)	1.24 (0.96-1.59)	1.23 (0.96-1.60)	0.78† (0.61-1.01)
	P<0.001	*P* =0.013	*P* =0.349	*P* =0.280	*P* =0.056	*P* =0.096	*P* =0.093	*P* =0.051
Gender	1.56 (0.91-2.68)	0.87 (0.53-1.41)	0.94 (0.57-1.53)	0.97 (0.60-1.57)	1.22 (0.76-1.99)	1.31 (0.81-2.12)	0.96 (0.59-1.56)	1.42 (0.88-2.29)
	P =0.109	*P* =0.573	*P* =0.795	*P* =0.901	*P* =0.412	*P* =0.275	*P* =0.861	*P* =0.148
Marital status	0.57 (0.31-1.01)	0.76 (0.45-1.29)	1.05 (0.62-1.77)	1.12 (0.67-1.88)	0.97 (0.58-1.62)	2.04* (1.21-3.34)	0.59* (0.35-1.00)	0.99 (0.60-1.64)
	P =0.056	*P* =0.307	*P* =0.851	*P* =0.658	*P* =0.916	*P* =0.007	*P* =0.048	*P* =0.971
CMT type	1.15 (0.63-2.12)	0.94 (0.54-1.64)	1.35 (0.77-2.38)	1.12 (0.65-1.95)	1.35 (0.77-2.34)	0.93 (0.53-1.60)	1.01 (0.57-1.77)	0.95 (0.55-1.64)
	P =0.655	*P* =0.840	*P* =0.297	*P* =0.683	*P* =0.296	*P* =0.781	*P* =0.983	*P* =0.858
Leg/foot weakness	6.68* (3.91-11.43)	2.40* (1.49-3.88)	1.58 (0.98-2.58)	2.69* (1.66-4.31)	1.98* (1.23-3.20)	2.05* (1.27-3.32)	1.11 (0.68-1.81)	2.23* (1.38-3.59)
	P =0.001	*P* =0.001	*P* =0.062	*P* =0.001	*P* =0.005	*P* =0.003	*P* =0.667	*P* =0.001
Leg cramps	2.02* (1.18-3.45)	1.94* (1.18-3.18)	3.65* (2.21-6.01)	2.02* (1.24-3.30)	2.00* (1.23-3.26)	1.76* (1.08-2.85)	1.86* (1.14-3.05)	1.50 (0.93-2.42)
	P =0.011	*P* =0.009	*P* =0.001	*P* =0.005	*P* =0.005	*P* =0.023	*P* =0.013	*P* =0.096

Values are odds ratio (95% CI) and *P*-value.

Physical SF-36 dimensions: physical functioning, impact of physical health on role performance (role physical), bodily pain, general health. Mental SF-36 dimensions: vitality, social functioning, impact of emotional health on role performance (role emotional), general mental health.

*Significant predictor of HRQoL dimension (*P*<0.05); †Note: Younger people reported worse mental health score

Australian CMT Health Survey

About you

Y1. **What is your gender?**

Male ❑ Female ❑

Y2. **What is your marital status?** (please tick one)

Single ❑ Married/ de facto ❑ Separated/divorced ❑ Widowed ❑

Y3. **What was your age last birthday?**

Y4. **At approximately what age did you first notice signs of CMT?**

Y5. **At approximately what age was your CMT formally diagnosed?**

Y6. **Were you incorrectly diagnosed as having another condition before being diagnosed as having CMT?**

No ❑ Yes ❑

Y6a. If yes, please give details. (Examples might include muscular dystrophy, polio, arthritis)

Y7. **Which type of CMT do you have?**

Not sure ❑ CMT1A ('hypertrophic' type) ❑ CMT1(other) ('hypertrophic' type – not chromosome 17) ❑

CMT2 ('axonal' type) ❑ CMT3 (Dejerine-Sottas) ❑ CMTX (the 'x-linked' form) ❑

Other

(please provide details)

Y8. **Have you had a genetic test for CMT?**

No ❑ Yes ❑

Y9. **Has your CMT type been confirmed by a genetic test?**

(either in you or an immediate relative) No ❑ Yes ❑

About your family

F1. **Is there a history of CMT in your family?**

No ❑ Not sure ❑ Yes ❑

F1a. If yes, please provide details.

F2. **Is yours considered a 'sporadic' case?**
(a one-off case with no family history)

No ❑ Not sure ❑ Yes ❑

F3. **Do you have any children?**

No ❑ Yes ❑

F3a. **How many children do you have?**

F3b. **How many of your children have CMT?**

F4. **Do you have any other significant medical problems in addition to your CMT?**

No ❑ Yes ❑

F4a. If yes, please provide details.

Please turn the page and continue

Women and pregnancy

If you are male, or a woman who has never been pregnant please skip this section and go straight to question B1 at the bottom of this page – 'CMT and your body'

P1. **Were you diagnosed with CMT before your 1st pregnancy**

No ❑ Yes ❑

P1a. **Did you receive any genetic counselling?**

Yes ❑ No ❑

P1b. **Would you have liked to have had some genetic counselling?**

No ❑ Yes ❑ Not sure ❑

P2. **For each of your pregnancies please indicate whether you experienced any worsening of your CMT symptoms while pregnant** (eg weakness, more severe muscle wasting, pins and needles etc) –please complete a line for each pregnancy. Once you reach the last of your pregnancies either tick the box marked "Not applicable' or leave the rest of the lines blank.

	Your age at the time	Not Applicable	No change	A little worse	Worse	Much worse	Very much worse
Pregnancy number 1	_____		❑	❑	❑	❑	❑
Pregnancy number 2	_____	❑	❑	❑	❑	❑	❑
Pregnancy number 3	_____	❑	❑	❑	❑	❑	❑
Pregnancy number 4	_____	❑	❑	❑	❑	❑	❑
Pregnancy number 5	_____	❑	❑	❑	❑	❑	❑
Pregnancy number 6	_____	❑	❑	❑	❑	❑	❑
Pregnancy number 7	_____	❑	❑	❑	❑	❑	❑
Pregnancy number 8	_____	❑	❑	❑	❑	❑	❑
Pregnancy number 9	_____	❑	❑	❑	❑	❑	❑
Pregnancy number 10	_____	❑	❑	❑	❑	❑	❑

If there was any change in your CMT due to pregnancy, please provide some information on the type of changes you experienced.

CMT and your body

Please indicate how severely you are affected by the following common features of CMT.

	Not at all	A little	A moderate amount	Quite a lot	Severely
B1. **Scoliosis** (a twist in your back)	❑	❑	❑	❑	❑
In your arms/hands -					
B2. **Weakness**	❑	❑	❑	❑	❑
B3. **Muscle wasting**	❑	❑	❑	❑	❑
B4. **Tremor**	❑	❑	❑	❑	❑
B5. **Sensitivity to cold**	❑	❑	❑	❑	❑
In your feet/legs -					
B6. **Weakness**	❑	❑	❑	❑	❑
B7. **Muscle wasting**	❑	❑	❑	❑	❑
B8. **Sensitivity to cold**	❑	❑	❑	❑	❑
B9. **Flat feet**	❑	❑	❑	❑	❑
B10. **High arches**	❑	❑	❑	❑	❑

Other (please comment)

Please turn the page and continue

CMT and your body - sensation

All of the questions in this section relate to how often you experience problems with sensation
Please tick the box which you feels best applies to you for each of the questions.

	Never	Occasionally	Often	Very often	Constantly
Do you have problems with your…					
S1. **Hearing**	❑	❑	❑	❑	❑
S2. **Vision** (with seeing)	❑	❑	❑	❑	❑
Do you suffer from loss of sensation in:					
S3. **Your hands**	❑	❑	❑	❑	❑
S4. **Your feet**	❑	❑	❑	❑	❑
Do you have any problems with any of the following?					
S5. **Bladder control**	❑	❑	❑	❑	❑
S6. **Bowel control**	❑	❑	❑	❑	❑
S7. **Sexual function**	❑	❑	❑	❑	❑
S8. **Do you burn yourself?** (eg your hands while cooking, or feet when stepping into the bath)	❑	❑	❑	❑	❑
S9. **Do you have slow reactions to pain?** (eg stub your toe and take quite a few seconds before noticing pain)	❑	❑	❑	❑	❑
Do you experience shooting pains?					
S10. **In your arms/hands**	❑	❑	❑	❑	❑
S11. **In your legs/feet**	❑	❑	❑	❑	❑
Do you experience 'pins and needles' or other strange sensations?					
S12. **In your arms/hands**	❑	❑	❑	❑	❑
S13. **In your legs/feet**	❑	❑	❑	❑	❑
S14. **Do you have 'cramps' in your legs? (cramps = <u>painful</u> spasms in the muscles)**	❑	❑	❑	❑	❑
S15. **Do you have 'restless' legs at night or when sitting?**	❑	❑	❑	❑	❑

<u>Please add any comments you would like to make about the changes in sensation associated with your CMT</u>

Please turn the page and continue

CMT and you – impacts on daily function

F1. **Do you use any of the following aids or devices?** (please tick all that apply)

Wheelchair	❑	**Mobility scooter**	❑
Walking stick	❑	**Walking frame**	❑
Orthoses (inserts in your shoes)			
Low-cut 'in-shoe' orthoses	❑	**Other orthoses**	
Splints coming above the ankle (back slab or AFO type)	❑	(please specify)	
Kitchen aids (jar openers, large handled cutlery etc)	❑	**Dressing aids** (shoe horns, button aids etc)	❑

Please add any comments you would like to make about aids and devices.

Many people with CMT have problems finding comfortable footwear. For the benefit of other members however, **if you have found a type of shoe or a supplier who you feel has helped you, please supply details below.** (**This information will not form part of the survey analysis but the list will be held by the CMTAA and provided to members.)**

	Never	Occasionally	Often	Very often	Constantly
Do you lose your balance when:					
L1. **You are walking on flat surfaces?**	❑	❑	❑	❑	❑
L2. **You are standing still?**	❑	❑	❑	❑	❑
L3. **You are walking on uneven surfaces?**	❑	❑	❑	❑	❑
L4. **Do you bend your knees to assist with your balance?**	❑	❑	❑	❑	❑
L5. **Do you fall to the ground because of balance problems**	❑	❑	❑	❑	❑

Please add any comments you would like to make about your CMT and daily function

CMT and you – treatments (non-surgical)

Please indicate which of the following treatments you have tried. It would be very helpful if you could indicate **how easy you found it to go through the treatment** and **how effective** the treatment was for you.

Have you tried:

C1. **Stretching exercises?**

No ❑ **Yes** ❑ **Approx date(s)**

Ease — No difficulty ❑ | Minimal difficulty ❑ | Difficult ❑ | Very difficult ❑ | Impossible ❑

Effectiveness — Useless ❑ | A little help ❑ | Quite helpful ❑ | Very helpful ❑ | 100% effective ❑

C2. **Ankle/foot splints (<u>daytime</u> wear)**

No ❑ **Yes** ❑ **Approx date(s)**

Ease — No difficulty ❑ | Minimal difficulty ❑ | Difficult ❑ | Very difficult ❑ | Impossible ❑

Effectiveness — Useless ❑ | A little help ❑ | Quite helpful ❑ | Very helpful ❑ | 100% effective ❑

C3. **Ankle/foot splints (<u>night-time</u> wear)**

No ❑ **Yes** ❑ **Approx date(s)**

Ease — No difficulty ❑ | Minimal difficulty ❑ | Difficult ❑ | Very difficult ❑ | Impossible ❑

Effectiveness — Useless ❑ | A little help ❑ | Quite helpful ❑ | Very helpful ❑ | 100% effective ❑

C4. **Shoe inserts (not above the ankle)**

No ❑ **Yes** ❑ **Approx date(s)**

Ease — No difficulty ❑ | Minimal difficulty ❑ | Difficult ❑ | Very difficult ❑ | Impossible ❑

Effectiveness — Useless ❑ | A little help ❑ | Quite helpful ❑ | Very helpful ❑ | 100% effective ❑

C5. **Plaster casts**

No ❑ **Yes** ❑ **Approx date(s)**

Ease — No difficulty ❑ | Minimal difficulty ❑ | Difficult ❑ | Very difficult ❑ | Impossible ❑

Effectiveness — Useless ❑ | A little help ❑ | Quite helpful ❑ | Very helpful ❑ | 100% effective ❑

C6. **Strengthening exercises** (<u>seated or lying down</u>)

No ❑ Yes ❑ Approx date(s)

Ease — No difficulty ❑ | Minimal difficulty ❑ | Difficult ❑ | Very difficult ❑ | Impossible ❑

Effectiveness — Useless ❑ | A little help ❑ | Quite helpful ❑ | Very helpful ❑ | 100% effective ❑

C7. **Strengthening exercises** (<u>standing</u>)

No ❑ **Yes** ❑ **Approx date(s)**

Ease — No difficulty ❑ | Minimal difficulty ❑ | Difficult ❑ | Very difficult ❑ | Impossible ❑

Effectiveness — Useless ❑ | A little help ❑ | Quite helpful ❑ | Very helpful ❑ | 100% effective ❑

CMT and you – treatments (alternative therapies)

Please indicate below if you have tried any alternative therapies (acupuncture, traditional Chinese medicine, naturopathy, aromatherapy, homoeopathy etc.) and indicate how easy you found it to go through the treatment and how effective the treatment was for you. If you have not tried any alternative therapies go straight to the next section.

Type of alternative therapy and date

A1.	**Ease**	No difficulty ❑	Minimal difficulty ❑	Difficult ❑	Very difficult ❑	Impossible ❑
	Effectiveness	Useless ❑	A little help ❑	Quite helpful ❑	Very helpful ❑	100% effective ❑
A2.	**Ease**	No difficulty ❑	Minimal difficulty ❑	Difficult ❑	Very difficult ❑	Impossible ❑
	Effectiveness	Useless ❑	A little help ❑	Quite helpful ❑	Very helpful ❑	100% effective ❑
A3.	**Ease**	No difficulty ❑	Minimal difficulty ❑	Difficult ❑	Very difficult ❑	Impossible ❑
	Effectiveness	Useless ❑	A little help ❑	Quite helpful ❑	Very helpful ❑	100% effective ❑

Please add any comments about the general conservative (non-surgical), **and/or** the alternative treatments you have tried.

CMT and you – treatments (surgery) foot only

Please indicate which of the following surgical treatments have been tried with you to improve your feet.
For many people there will be a complex history of several different approaches on several occasions. For the sake of keeping the form a manageable size, the list of options has been kept to a minimum.
If you wish to continue on a separate sheet please feel free to do so. (If you do add extra sheets listing multiple episodes of surgery, it would help us enormously if you can use the same format as in the questionnaire.)

In this section you are asked to tell us the approximate year you had the various surgeries, what age you were, what type of surgery you had and where, how traumatic the process was, how effective was the surgery technically, and how worthwhile you now consider subjecting your self to the surgery. In deciding how traumatic it was undergoing the surgery you should include: the amount of pain you suffered, the impact on your day-to-day life while you were healing from the surgery, and the length of time you were disabled by the surgery.

Please put a number in the box corresponding to the type of surgery you had, and then score your experience of the surgery.

11 Muscle/tendon surgery – not sure what kind **12** Bone surgery (osteotomy) – not sure what kind **13** Joint fusion – not sure what kind	**21** Tendon lengthening without transfer to a different place **22** Tendon or muscle transfer without bony surgery	**31** Bone surgery (osteotomy) without any joints fused- many bones operated on at the same time **32** Bone surgery (osteotomy) without any joints fused- heel only **33** Bone surgery (osteotomy) without any joints fused- arch area only **34** Bone surgery (osteotomy) without any joints fused – front of foot only **35** Bone surgery (osteotomy) and muscle/ tendon lengthening or transfer **36** Toe straightening	**41** Joint fusion – 'Triple arthrodesis' **42** Joint fusion – Ankle **43** Joint fusion – Heel **44** Joint fusion – Arch area **45** Joint fusion – Front of foot only **50** Other – (please specify)

EXAMPLE

Surgery type, place and approx date

22 – tendon transfer –aged 17 (1980) West Coast Hospital, Sydney

Trauma	None	Some but manageable	Unpleasant	Very unpleasant	Terrible
	❑	❑	☒	❑	❑
Effectiveness	Useless	A little help	Quite helpful	Very helpful	100% effective
	❑	☒	❑	❑	❑
Worthwhile	Definitely no	Not really	Neutral	Yes	Definitely yes
	❑	❑	☒	❑	❑

Comments

It was very painful at first. I was able to walk within a month though so it could have been worse. It didn't really work as I have had to have a joint fusion since, but I suppose it bought me some time.

S1. **Surgery type, place and approx date**

Trauma	None	Some but manageable	Unpleasant	Very unpleasant	Terrible
	❑	❑	❑	❑	❑
Effectiveness	Useless	A little help	Quite helpful	Very helpful	100% effective
	❑	❑	❑	❑	❑
Worthwhile	Definitely no	Not really	Neutral	Yes	Definitely yes
	❑	❑	❑	❑	❑

Comments

S2. **Surgery type, place and approx date**

Trauma	None ❑	Some but manageable ❑	Unpleasant ❑	Very unpleasant ❑	Terrible ❑
Effectiveness	Useless ❑	A little help ❑	Quite helpful ❑	Very helpful ❑	100% effective ❑
Worthwhile	Definitely no ❑	Not really ❑	Neutral ❑	Yes ❑	Definitely yes ❑

Comments

S3. **Surgery type, place and approx date**

Trauma	None ❑	Some but manageable ❑	Unpleasant ❑	Very unpleasant ❑	Terrible ❑
Effectiveness	Useless ❑	A little help ❑	Quite helpful ❑	Very helpful ❑	100% effective ❑
Worthwhile	Definitely no ❑	Not really ❑	Neutral ❑	Yes ❑	Definitely yes ❑

Comments

S4. **Surgery type, place and approx date**

Trauma	None ❑	Some but manageable ❑	Unpleasant ❑	Very unpleasant ❑	Terrible ❑
Effectiveness	Useless ❑	A little help ❑	Quite helpful ❑	Very helpful ❑	100% effective ❑
Worthwhile	Definitely no ❑	Not really ❑	Neutral ❑	Yes ❑	Definitely yes ❑

Comments

Please continue on a separate sheet if necessary (in the same format if possible)

Please turn the page and continue

CMT and you – treatments (surgery) foot only

Please tell us about the <u>three most successful</u> approaches to treatment you have tried. Please try to include why these approaches have been more successful than others.

M1

M2

M3

Please tell us about the <u>two least successful</u> approaches you have tried. Please try to include why these approaches have been less successful than others.

U1

U2

<u>Please feel free to add any other comments regarding you, your experiences with CMT, or this survey</u> (continue on a separate sheet if necessary).

Thank you for taking the time to fill out this questionnaire.