

**WEEKEND CAMP FOR YOUNG PEOPLE
FROM FAMILIES WITH HUNTINGTON'S DISEASE
27- 30 January 1994
Report by Dorothy Tortell**

INTRODUCTION

As a result of encouragement from parents, the Wellington Huntington's Disease Association organized a **Weekend Camp** for young people from families with Huntington's Disease. The Camp was held in the Wairarapa with activities organized by the Wairarapa Outdoor Recreation Trust in addition to discussion groups run by an experienced Counsellor/Facilitator. The Camp started on Thursday 27 January in the evening and finished on Sunday 30 January in the afternoon with families and friends having joined the young people for lunch. After some withdrawals and some late registrations, the final number of campers was 18.

CAMP OBJECTIVES

The Camp had the following Objectives -

- !For young people from families with Huntington's Disease to meet others from similar background circumstances
- !For the young people to share information and experiences about Huntington's Disease
- !For the young people to support each other and by doing so, develop a mutual support network
- !For all the participants to have fun

The Camp was a great success and all the objectives are considered to have been met. Campers managed to meet other young people in the same situation and learn how they coped; they spent time with other people who understand what they are going through and gained support from people in the "same boat"; they made new friendships and overcame feelings of isolation; and they shared information and through this, gained new confidence.

CAMP ORGANIZATION

Venue	Ararangi Campsite, Masterton
Outdoor Activities arranged and supervised by	Wairarapa Outdoor Recreation Trust (WORT)
Camp organized by	Dorothy Tortell, Wellington HDA Social Worker
and	Judy Lyon, Wellington HDA Chairperson
Counsellor/Facilitator	Ann-Marie Stapp
Accompanying adults	David Lyon Philip Tortell Lisa Tortell
Other adult helpers	Brigit Lyon John Schiff

PLANNING PROCESS

- September 1993 ! Discussions with WORT started.
! Suggested format and quote for the proposed Camp received from WORT.
! Invited Ann-Marie Stapp to join the Camp as the Counsellor/Facilitator.
! Sent out initial information and Registration Forms to all young people from HD families in the Wellington area and to all contact people throughout NZ (Social Workers).
- Sep to Dec 1993 ! 15 completed Registration Forms received.
- November 1993 ! Began writing to agencies for financial assistance for the camp. As soon as help was made available, thank you letters were sent out.
! Wrote to each camper thanking them for sending me the completed forms, giving them more information on the camp and asking them to fill in a Health Form.
! Final planning session held with Ann-Marie.
- December 1993 ! Visited Ararangi Camp and finalized plans for outdoor activities with WORT in early Dec.
! Before Christmas, 2 more young people registered, bringing the number to 17 campers.
- January 1994 ! Sent out an update on the camp in early Jan to all those registered. Included in this was a list of things to bring to the camp.
! 26 January (eve of the Camp) - final visit to Ararangi Campsite and WORT.
! 26 January - one more camper registered, bringing the total number of participants to 18.
! 27 January - Camp started.

FUNDING AND COSTS

AGENCIES APPROACHED FOR FINANCIAL ASSISTANCE -

- ! Lions Clubs (Wellington)
- ! Air New Zealand Ltd
- ! Ansett New Zealand Ltd
- ! McDonald's Family Restaurant, Masterton
- ! Transit Coachlines (Wellington) Limited
- ! Ahradsen's Bookshop, Wellington
- ! Pub Charity

FINANCIAL SUPPORT RECEIVED -

- ! McDonald's Family Restaurant, Masterton - substantial reduction for 25 takeaway meals
- ! Transit Coachlines (Wellington) Limited - reduction in one way bus ticket for 2 young people
- ! Ahradsen's Bookshop - donation of address books/diaries and name tags for each participant
- ! Pub Charity - donation of pocket knife, ballpen and playing cards for each participant
- ! Verna and Doug Curry - donation of sausages and cakes

- ! Selling of raffle tickets by Verna Curry - \$200
- ! Comalco NZ. - \$550
- ! Auckland Huntington's Disease Association - \$175

CAMP COSTS

! Facilitator/counsellor	\$ 500.00
! Airfare for counsellor	146.00
! Part payment for McDonald's meal	50.00
! Help with bus fare for 2 participants	20.00
! Wairarapa Outdoor and Recreation Trust	1,750.00
! Extra food	22.50
! Stationery	24.45
TOTAL	\$ 2,512.95

All funding support is gratefully acknowledged. The balance was met from the Wellington Huntington's Disease Association's funds.

PARTICIPANTS

The total number of campers was 18 (10 females and 8 males)
4 family groups made up a total of 10 young people

Age range 6 - 16 years -

6 years	one camper	7.5 years	one camper
8 years	one camper	9 years	one camper
10 years	two campers	11 years	two campers
12 years	four campers	13 years	one camper
14 years	one camper	15 years	two campers
16 years	two campers		

Districts the participants came from were -

one from Auckland	one from Hamilton	two from Wanganui
nine from Wellington	three from Nelson	two from Invercargill

CAMP PROCEDURE

Anne-Marie worked with the campers each morning for an hour before the outdoor activities began and again for a short time before dinner. After dinner, she continued her programme for approximately another hour. Her very exciting and well planned programme included activities to improve decision-making and problem solving, a better understanding of disabilities, confidence building, increasing self esteem and discussions on feelings.

WORT activities were held on Friday and Saturday from 10.30am to approximately 5.00pm.

Thursday

- ! The 5 campers from the South Island (Invercargill and Nelson) were met at the airport by Dorothy and Philip. They were driven around Wellington by Philip and shown some of the sights.
- ! Dorothy collected the 2 campers arriving from Wanganui and 2 campers from Wellington.

- ! These 9 campers had lunch at Dorothy and Philip's place before leaving for Masterton on transport provided by Dorothy, Philip and John Schiff who also picked up a Titahi Bay camper.
- ! Judy and Brigit Lyon collected 6 campers from Stokes Valley and Upper Hutt.
- ! In total, 16 campers travelled from Wellington to Masterton in 5 cars.
- ! The Auckland and Hamilton campers travelled together by private car directly to Masterton.
- ! On arrival at the campsite the campers were assigned to bunk rooms and given time to unpack and settle in. Bunk rooms were allocated according to age and sex.
- ! Campers introduced themselves to each other.
- ! A belt bag containing ballpen, pocket knife, diary/address book and a pack of playing cards was given to each camper.
- ! WORT staff explained the various activities the campers will be able to do over the weekend.
- ! The objectives, rules and roster of duties were discussed and agreed to.
- ! The rest of the evening was free time to allow campers to get to know each other.

Friday

8.00am - 9.00am Breakfast and preparation for outdoor activities.

9.00am - 10.00am Ann-Marie worked with the campers preparing them for the outdoor activities.

10.30am - 5.00pm Outdoor activities with WORT; the campers were divided into 2 groups according to age so their abilities were more or less equal and all activities for the day were done in these groups. Each camper had a turn at horse riding, canoeing, sailing, kayaking and caving.

After dinner Activities with Ann-Marie. The campers were asked to write down 3 questions each on Huntington's Disease. Half the questions were answered that evening by Judy and the rest were answered the next evening.

Saturday

8.00am - 9.00am Breakfast and preparation for the day's outdoor activities.

9.00am - 10.00am Activities with Ann-Marie.

10.00am - 6.00pm Outdoor activities with WORT which included whitewater rafting and abseiling.

7.30pm Activities with Ann-Marie and a concert.

More questions were answered on Huntington's Disease.

Sunday

8.00am - 9.30am Breakfast, packing and cleaning.

9.30am - 12.00noon Activities with Ann-Marie; evaluation of camp.

11.00am Families begin to arrive.

12.00noon Barbeque Lunch with families able to travel to Masterton.

2.45pm Breakup of camp.

EVALUATION OF THE CAMP

All campers completed an evaluation form with the following results -

Q 1. How the campers rated the daily activities (Excellent, Good or Poor)

	EXCELLENT	GOOD	POOR	NO ANSWER
Thursday evening	7	13	0	0

Friday am at the camp	5	13	0	0
Friday outdoor activities	17	1	0	0
Friday evening	11	7	0	0
Saturday am at the camp	9	9	0	0
Saturday outdoor activities	18	0	0	0
Saturday evening	13	4	0	1
Sunday am at camp	12	6	0	0
BBQ Lunch with families	10	2	0	6

Q 2.All 18 campers said they were happy with the amount of organized activities, but 14 campers would have liked more free time.

Q 3.When asked which activities they would leave out in order to have more free time, campers replied as follows -

no suggestions as to what could be left out	9
leave out morning indoor sessions	6
leave out abseiling	2
leave out caving	1

Q 4.15 campers found it very helpful being able to talk to other campers about Huntington's Disease, while 2 found it quite good and one did not answer the question.

Q 5.Was the Room Group system helpful? - 7 found it very helpful; 8 quite helpful; 3 not helpful. 4 campers added a comment that they felt the cabins should be mixed.

Q 6.How did they rate the accomadation? - 5 very comfortable; 8 comfortable; 5 uncomfortable.

Q 7.How was the food? 13 said the food was good and enough;
1 said the food was good but not enough;
4 thought the food was not so good.

Q 8.12 campers found the adult helpers friendly and helpful; 1 found the helpers just OK, while 5 found some of the helpers friendly and helpful and some just OK.

Q 9.All 18 campers found the camp rules fair and reasonable.

Q10.All 18 campers think the camp should take place again next year and they would all like to take part in it.

CONCLUSIONS

! The camp was a resounding success.

! All the objectives were met.

! I feel the Association has a responsibility to continue running such camps in the future.

! Therefore fund raising should begin immediately.

! If the Wellington Association is to organize the next camp, I feel it should be held once again in the Wellington/Wairarapa region for ease of planning.

! I believe that a facilitator/counsellor such as Ann-Marie should be contracted again to work with the young people. Ann-Marie's input into the camp was invaluable; the time she spent on preparation for the Camp and her wonderful interaction with the young people was a major contribution to the camp's success.

! Outdoor activities for such a camp are essential and must be continued and extended. WORT played a big part in the success of the Camp. The instructors were excellent, relating well to the young people and adult helpers.

! I would suggest we should do our own catering at the next camp.

! If at all possible, the younger campers should be in cabins away from the older campers so that the former can get more sleep.

! I would not recommend mixed cabins as suggested by 4 campers.

! The possibility of a longer camp should be considered, which would make more free time available.

! It is important that the families are involved in the camp either in the beginning or the end. I would suggest the involvement of family members for the whole of the final day, finishing with a joint session for family members and campers.

! Transport from Wellington to the venue would be made easier by hiring a bus.

! A questionnaire should soon be sent out to all those interested in the next camp, asking them when is their preferred time for the next camp. This questionnaire should also be put in the Association's Newsletter.

The young people left the camp more confident, with an increased knowledge of Huntington's Disease, and with a well established support network which I hope will continue for many years to come.

ACKNOWLEDGEMENTS

My sincere thanks to all those who helped make this camp possible - to those who helped us financially, to those that gave us moral support, and to those who gave up their time to help at the camp.

My thanks also to all the campers who got into the spirit of the camp right away and who participated fully and sincerely in all the activities. I really enjoyed meeting you all and sharing the weekend with you. I look forward to being with you at the next camp.

Dorothy Tortell
Social Worker