

LipoedAme, a multidisciplinary lifestyle pilot project Lipedema in Amerongen, the Netherlands

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Introduction	We've followed 8 women diagnosed with lipedema, who were unhappy with their body and lifestyle, for a period of 6 months
Aim	To see the impact on quality of life (QoL) and physical activities by providing a free multi-disciplinary targeted health program
Rationale	A tailor made health program together with peers, might improve a more healthy life, QoL and positively impact their daughters life in future
Description	<p>A weekly program of 1,5 hour of physical exercises in our gym and a 'walking group' for 1 hour were provided. Every 4 weeks we have offered an additional introduction hour of other physical activities, like Yoga, Tai Chi, Pilates, dancing on music, etc. and a dietician attended for questions and advice. Psychological support was provided and follow up was available on request.</p> <p>Tips, tricks and walking appointments were shared in a group chat.</p> <p>AD compression stockings (TEK) were provided for those diagnosed with lip-lymphedema.</p> <p>We measured the physical condition (weight, sizes, muscle tissue and strength, 6MWT, etc.) QoL questionnaires (SF-36 and MVI) and weekly minutes of physical activities and used a body bio impedance measurement at 0 and 6 months</p>
Results	<p>After 6 months we were able to evaluate 6 participants:</p> <ul style="list-style-type: none"> • increase on QoL (average: SF-36: 11,7 points and MVI: 0,67), • increase of total number of physical activities with an average of 154 minutes per week and we found a positive impact on extracellular moisture • increase of muscle strength and condition • 4 out of 6 continued with tailor-made compression stockings as their fatigue and complaints of their legs improved positively
Evaluation 5 months later	<p>5 Participants still have a higher level of physical activities, are happy that they have participated in this pilot project and will advise others positively to do so</p> <p>The 'walking group' still exists, one participant goes to work by bike (20 km) and another takes dances class every week.</p>
Conclusions	<ul style="list-style-type: none"> • multi-disciplinary approach and peer support are both important success factors to start and continue with weekly physical exercises and a more healthy life style • these changes have a positive impact on QoL (measured by SF-36 and MVI) • monthly coaching by dietician is an important part of eating healthy and lifestyle change • introduction of new kind of physical activities with peers might stimulate to start (new) physical activities
Discussions	<ol style="list-style-type: none"> 1. We found an increase of muscle strength and condition, but no muscle mass increase was seen by the bio impedance measurement at 6 month. A training schedule of once weekly to increase muscle mass is not enough. Therefore we would recommended a training schedule at least twice a week for physical exercises in a gym 2. The role of a dietician turned out to be very successful and well appreciated by the participants as they had a lot of questions and misunderstandings regarding healthy food, drinks and diets 3. AD compression stockings for those suffering from lymph-lipedema might have a positive impact on continuation of physical exercises
References	<ol style="list-style-type: none"> 1. 'Klinische criteria voor het stellen van de diagnose lipoedeem' gebruikt uit de Samenvatting Richtlijn Lipoedeem Dermatologie 2015 2. Multidisciplinaire evidence-based richtlijn 01-05-2014 3. nvdv.nl richtlijn lipoedeem 2015 4. www.nijsmelinghe.nl 5. CME Lipoedeem: Diagnostiek en behandeling. J. Bosman

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Year of birth (height)	BMI sept-mrt	weight	extra cel H2O	increase steps p/d	increase activities p/w (min)	PSK1	VMI	SF-36
1961 (1.64)	41,6 - 34,7	-18,7	-0,3	5000	160	-72	1,2	14
1974 (1.68)	36,9-36	-2,5	-0,5	15000	252	-25	0	7
1973 (1.79)	37,9-38	0	-2,1	na	50	-25	-1,4	7
1977 (1.64)	42-42,5	1,4	-1	986	-25	-25	na	7
1961 (1.73)	35,8-36,2	1,4	0,9	na	25	-95	-3,4	12
1973 (1.78)	27,5-28-3	2,6	1,4	500	0	na	-0,4	23

Tabel: Delta in measurements base case Sep 2016 and end of pilot Mar 2017