Preparingforlife
Preconception Care Worldwide

A GLOBAL INITIATIVE TO PROMOTE PRECONCEPTION CARE

Report
Preparatory Meeting on Preparing for Life

The Hague, 21 - 23 March 2010

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Preparing for Life is grateful for the generous contributions and efforts of the following organisations whose invaluable support made possible its inception and this preliminary meeting:

1. The initiative

In March 2010, just prior to the preliminary meeting on Preparing for Life, the United Nations Secretary General Ban Ki-moon in his Millennium Development Goals (MDG) Report "Keeping the Promise" noted many countries would not achieve their target with respect to childhood mortality, the poor global progress in reducing maternal mortality, and the continuing chalellenges with HIV/AIDS infection. To accelerate progress for the health-related Millennium Development Goals (4, 5 & 6) he recommended the strengthening of national health systems to improve maternal and child health with the the active participation of civil society organisations.

Preparing for Life is a new initiative, open to international organisations, government bodies, non-governmental organisations, academics, industry and individuals. It aims to promote international awareness and the development of programmes for preconception care, particularly in middle and low-income nations. Preconception care is the full range of effective interventions, focused primarily on the health of women of reproductive age, and their partners, prior to or between pregnancies that promote the opportunity for safe motherhood and the birth of a healthy infant with the expectation of healthy longevity. Therein its first objective is to help reduce maternal and childhood mortality and morbidity, thereby contributing to the achievement of the United Nations Millennium Development Goals.

At its first meeting, in The Hague in March 2010, Preparing for Life agreed, in the first instance, to bring together committed organizations, including patient organizations, and individuals at an international level to develop an international consensus on the need for and requirements of an action plan for the global promotion and implementation of preconception care.

UNITED NATIONS HEALTH MILLENNIUM DEVELOPMENT GOALS

CHILD MORTALITY
Reduce by ⅔, between 1990 and 2015 the under 5 mortality rate.

MATERNAL HEALTH
Target 1. Reduce by ¾ the maternal mortality ratio.
Target 2. Achieve universal access to reproductive health.

COMBAT HIV, MALARIA & OTHER DISEASES
Have halted by 2015 & begun to reverse the spread of HIV/AIDS.

2. Report Preparatory meeting on Preparing for Life

Background

At the request of the Dutch Minister for Health, Welfare and Sport, the Health Council of the Netherlands, in collaboration with the Dutch Cochrane Centre, undertook a systematic review of the scientific literature on preconception care. Based on this, evidence-based recommendations were developed and a program of preconception care, including ethical considerations, was proposed in the Health Council's advisory report "Preconception care: a good beginning" (The Hague, 2007).

Included in the Minister's mandate to the Health Council of the Netherlands was the request to determine to what extent available knowledge was being applied in the Netherlands and elsewhere. Recognising from the advisory report the global potential for preconception care to contribute to the improvement of maternal and childhood mortality and morbidity the Vereniging Samenwerkende Ouder- en Patientenorganisaties (VSOP) instigated a meeting of a small group of international experts in The Hague. This was hosted by the Health Council of the Netherlands. The purpose of the meeting was to launch "Preparing for Life", a global initiative to promote preconception care.

In view of its advisory report "Preconception care: a good beginning" the Health Council of the Netherlands has endorsed this initiative. This report summarises the recommendations and action steps endorsed by this meeting.

Introduction

Preconception health should be an essential component of maternal and child health promotion. Each day over 1400 women die from pregnancy and childbirth related causes. Almost all (99%) of these over half a million women die in middle- and low-income countries and their deaths are avoidable. Of the 10.4 million annual childhood deaths, 3.85 million (37%) are neonates of which approximately 1.2 million (31%) die as a consequence of preterm delivery or low birth weight and some 300 000 from congenital anomalies. (UN Millennium Development Goals Report, 2009; Global Burden of Disease, 2004). Considerably more children with congenital disorders are diagnosed and die after the neonatal period. (March of Dimes Global Birth Defects Report, 2007). Many of these maternal and childhood deaths, and other adverse pregnancy outcomes, are preventable with preconception care.

Traditionally initiatives to prevent maternal and childhood mortality and morbidity are focused on the prenatal and perinatal periods. Over the last three decades there has been increasing awareness that a significant proportion of maternal and child mortality and morbidity can be prevented and maternal and child health promoted by measures undertaken prior to conception. This preconception care is defined as the full range of effective interventions, focused primarily on the health of women of reproductive age, and their partners, prior to or between pregnancies that promote the opportunity for safe motherhood and the birth of a healthy infant with the expectation of healthy longevity.

Thus preconception care is multi-disciplinary and encompasses interventions targeted at risks consequent on lifestyle choices, nutrition, environmental and working conditions, illness, infection, medication and genetic factors. By promoting preconception health and understanding of risks implicit in conception, pregnancy, birth and subsequent life the opportunity is afforded to reduce maternal mortality and morbidity, and decrease the possibility of intrauterine death, preterm delivery, congenital disorders[1] and complex disorders of later life[2].

Guiding Principles Of The Preparing For Life Initiative

Central to the Preparing for Life initiative is helping to achieve the health Millennium Development Goals 4 (child health) and 5 (maternal health). Millennium Development Goal 6, combating HIV/AIDs can also be positively influenced.

Effective preconception care programmes can only be accomplished by the development of a strategy that reflects global, regional, national and local dimensions, including ethical, legal and social issues. It must be evidence based to generate resources and assure sustainability, and flexible enough to be adaptable to accommodate local priorities.

Preconception care has not been widely implemented because its aims and objectives are not widely understood and accepted and its capacity for benefit remains largely unrealised. There are many steps that can be taken by women, families, health care providers and public health authorities that are effective, inexpensive and which health care systems, including those in middle- and low-income nations, can implement.
Preconception care programmes must be based on a systematic health needs assessment. This includes an assessment of health needs[3], consideration of the knowledge, attitudes and practices in the community/society in question, the resources available and necessary to achieve change and of possible constraints, political, ethical, legal, and social. The challenge for health care authorities and providers is then to prioritise local health needs that can be served by preconception care interventions.

Preconception care programmes should provide effective choices for woman and couples to improve their reproductive options, and to maximise the avoidance of adverse outcomes in pregnancy, childhood and later life. Interventional programmes need to be structured in ways that demonstrate social solidarity across the community, and should be accessible to groups

[1] A congenital disorder is a structural or functional abnormality present from birth. A serious congenital disorder can cause death or disability. Congenital disorder is considered to have the same definition and can be used interchangeably with the term birth defect. (Management of Birth Defects & Haemoglobin Disorders. Report of a joint WHO-March of Dimes Meeting. WHO, Geneva, Switzerland. 2006).

[2] Complex disorders develop after birth, some manifesting in childhood but most in mid & later life. They are complex because their aetiology is multifactorial, with the environmental component being mostly postnatal. They are clinically complex, being systemic & involving different organs & systems. They include a wide range of diseases including common disorders like cancer, cardiovascular disease, diabetes, hypertension, mental disorders and stroke.

[3]A health need is a population's ability to benefit from an intervention or service. It is a function of both the prevalence of the problem under consideration and the effectiveness of the intervention(s) or services- health care, social, legal or policy development- available for the health need. The intervention or services may be one or a combination of the above components. Problems and disorders which have no effective remedies, no matter how common, have no need, whilst low prevalence problems and disorders with available effective interventions are considered as being problems of lesser need.

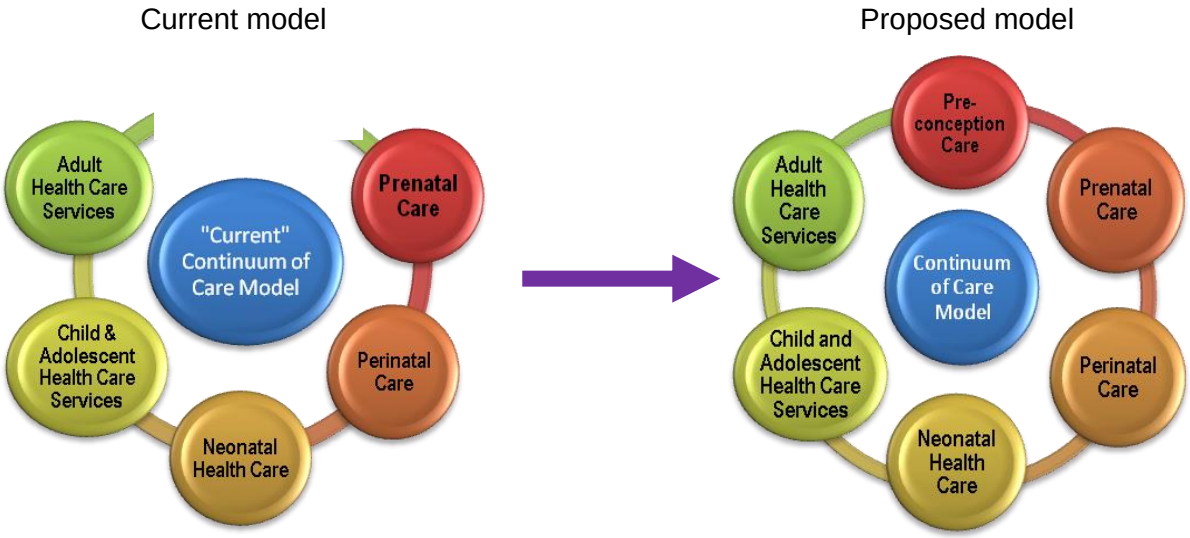
that are hard to reach - notably the poor, those from ethnic minorities and those with different cultural or religious beliefs. Culturally competent delivery is essential if women and couples are to feel they have choices, and so be willing to engage with effective preconception care programmes.

Strategic Aims Of The Preparing For Life Initiative

The meeting concurred that the following aims were central to the Preparing for Life initiative:

- To promote international awareness and the development of programmes for preconception care.
- To shift the paradigm for effective maternal and child health programmes from a focus on pre- and postnatal care to a paradigm that acknowledges that the avoidance of mortality and morbidity and the promotion of health for pregnant women and their children starts in the preconception period. It requires that risk factors which influence the health of the mother and baby-to-be, in pregnancy, infancy and childhood are addressed before the baby is conceived.
- Preconception care must be integrated into the traditional prenatal, perinatal, neonatal and child health services continuum of care. This should be achieved by implementing preconception care into existing programmes and services, particularly in primary health care.

Continuum of care model



Action Plan

Creation Of A Multi Stakeholder Consortium

The Preparing for Life initiative seeks to create an international multi-stakeholder consortium committed to promote preconception care globally with an emphasis on middle- and low-income countries.

Key stakeholders could include:

- World Health Organization (WHO)
- United Nations Children's Fund (UNICEF)
- UN Population Development Fund (UNFPA)
- World Bank
- European Science Advisory Network for Health (EuSANH)
- Center for Disease Control & Prevention (Atlanta, USA)
- World Alliance of Organisations for the prevention & treatment of genetic & congenital disorders (WAO)
- International Genetic Alliance (IGA)
- March of Dimes (MoD)
- International Clearinghouse for Birth Defects Surveillance & Research (ICBDSR)
- EUROCAT
- Academics

During the preparatory meeting a Consortium was established to develop the Preparing for Life action plan. This Consortium is open to additional membership.

An Executive Committee has been put in place to execute the Consortium's policy and sub committees and task groups have been established to assist the Executive Committee accomplish its mandate.

Sub Committees And Task Groups

1) Administration support
2) Development of an expert meeting
3) Funding
4) Review of past & current preconception policy statements, position papers, reports, literature and programmes
5) Engagement with relevant national and international professional societies
6) Website development for Preparing for Life

International Expert Meeting

The next step to implement the Preparing for Life initiative globally will be a meeting of invited international experts. This proposed meeting will bring committed organisations, including patient organisations, and academics. It will be tasked with:

- The production of a consensus document which aims to outline a framework of preconception care delivery, and the requirements for monitoring frameworks that will help secure evidence of health gain and so ensure sustainability.
- Production of a 'road map' of activity needs to be planned and agreed for how Preparing for Life can be conveyed to regional organisations and through them to national governments, health policy planners and appropriate practitioners.
- Update the available knowledge of validated risk factors and the worldwide occurrence and exposure to known risk factors in women of reproductive age.
- Review of prevention policies focused on these risk factors and their impact.
- Identification of knowledge gaps and barriers to the effective implementation of preconception care programmes in different regions and countries.
- Identification of means to increase synergies amongst organisations involved in the promotion of preconception care.
- Funding for the Preparing for Life initiative.

Possible representation in an expert meeting:

- International agencies (WHO, UNICEF, UNFPA, World Bank, EuSANH)
- National agencies (CDC, US AID)
- Patient organisations (International Genetic Alliance (IGA), International Alliance of Parent and Patient Organisations (IAPO))
- International Professional organisations (of Obstetrics & Gynaecology, Human Genetics, Midwifery, Paediatrics, Pharmacists, Family Medicine)
- NGOs (WAO, MoD)
- Registries (ICBDSR, EUROCAT)
- Regional/national experts
- Experts in women & reproductive health, health policy development and health economists

The maximum size of this expert meeting should not exceed 50 delegates, and ideally should be nearer 30 to allow for discussion and to avoid the descent into a series of set piece speeches. To facilitate engagement with WHO it could be held in Geneva, though The Hague would also provide a suitable venue.

3. Addenda

A. References

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United Nations. The Millenium Development Goals Report 2009. (2009)
[www.un.org/millenniumgoals/pdf/MDG%20Report%202009%20ENG.pdf]

World Health Organisation. The Global Burden of Disease 2004 Update. (2004)
[www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf]

March of Dimes. (2006) Global Report on Birth Defects.
[www.marchofdimes.com/globalprograms]

B. Participants Preparatory Meeting

Planning meeting Preparing for Life
Health Council of the Netherlands
The Hague, 21 - 23 March 2010

Prof. Arnold Christianson (Chairman) — Johannesburg
National Health Laboratory Service & University of the Witwatersrand
World Alliance Organizations for Prevention and Treatment
of Genetic and Congenital Conditions

Prof. Gouke Bonsel — Rotterdam
Erasmus Medisch Centrum

Mrs. Martha Carvalho — Sao Paulo
Brazilian Genetic Alliance
International Genetic Alliance

Prof. Martina Cornel — Amsterdam
VU University Amsterdam

Drs. Semiha Denktas — Rotterdam
Erasmus Medisch Centrum

Drs. Pepita Groeneveld — Den Haag
Public Health Department
Ministry of Health, Welfare and Sport

Mrs Karin Grootveld — Soest
VSOP – Dutch Genetic Alliance
Conference assistant

Dr. Chris Howson — New York
March of Dimes

Prof. Leo ten Kate — Amsterdam
Health Council of The Netherlands
Dutch Foundation for Preconception Care

Mr Alastair Kent — London
Genetic Alliance UK
EGAN - Patients Network for Medical Research and Health

Prof. André Knottnerus	Den Haag
Health Council of the Netherlands European Science Advisory Network for Health (EuSANH)	
Dr. Pierpaolo Maistroiacovo	Rome
International Clearinghouse for Birth Defects Surveillance and Research	
Prof. Irmgard Nippert	Munster
World Alliance of Organizations for Prevention and Treatment of Genetic and Congenital Conditions University Munster	
Dr. Cor Oosterwijk	Soest
VSOP - Dutch Genetic Alliance EGAN - Patients Network for Medical Research and Health	
Mr Ysbrand Poortman	Den Haag
"Preparing for Life" - initiative group International Genetic Alliance	
Dr. ir. Veronique Ruiz van Haperen	Den Haag
Health Council of the Netherlands	
Prof. Jacques Scheres	Maastricht
Rotary Netherlands European Centre for Disease Prevention and Control	
Prof. Régine Steegers	Rotterdam
Erasmus Medisch Centrum Endowed chair in Perinatal Epidemiology	
Dr. Edwin Trevathan	Atlanta
Centers for Disease Control and Prevention	
Prof. Pauline Verloove	Leiden
Rotary Netherlands Netherlands Organization for Applied Scientific Research	

C. Executive Summary Preconception Care: A Good Beginning.

Health Council Of The Netherlands Advisory Report, 2007.

Request for advice

Recent years have seen increasing attention focused on preconception care as a means of promoting the health of prospective parents and their children. It was this trend, together with the persistence of relatively high perinatal mortality in the Netherlands, that prompted the Minister of Health, Welfare and Sport to request that the Health Council produce an advisory report on preconception care.
The Minister asked the Council to review the current level of knowledge concerning preconception care. He also wished to know to what extent the available knowledge is already being applied, both in the Netherlands and elsewhere. A further question raised was which specific requirements a programme of preconception care would need to meet. Finally, the Minister asked the Health Council to investigate how one might reach the maximum possible number of parents-tobe, what professional groups and other bodies would need to be involved, and what ethical considerations arise in connection with preconception care.
In collaboration with the Dutch Cochrane Centre, a systematic review has been conducted of the scientific literature, using preconception care as the principal search term. This has generated a limited selection of topics on which sufficient literature with the highest level of evidence is available. In the light of the results, evidence-based recommendations have been made with regard to food, alcohol, tobacco and other recreational drugs, working conditions, illness and medication. Also discussed are genetic factors and ethical and legal matters. Finally, the Committee that produced this advisory report outlines a programme of preconception care which it advises the Minister to introduce in the Netherlands.

One concept, many forms

The aim of preconception care is, first and foremost, to improve the health of mother and child. Any public health benefits and cost savings are important spinoffs.
Preconception care is defined in this advisory report as the entire raft of measures to promote the health of the mother-to-be and her child. If they are to be effective, these measures should preferably be undertaken prior to conception.
Preconception care is therefore multidisciplinary, encompassing lifestyle (including food, drink, tobacco and other recreational drugs), working conditions, illness, medication and genetic factors.
Preconception care has various, complementary forms. Some are aimed at individual parents-to-be, while others may, for example, collectively target all women of child-bearing age.
Individual preconception care can either be of a general or specialist nature.
One general measure is the so-called preconception consultation, whereby couples who would like to have a child have a discussion with a GP or midwife. After having identified and assessed the risk factors, he/she gives them a combination of advice that is aimed at changing behaviour (e.g. to stop smoking) and non-directive information aimed at promoting their freedom of choice (e.g. about genetic testing). If necessary, prospective parents can then also be referred for specialist preconception care. This applies to situations where there is an increased risk either of complications during the pregnancy or of an adverse pregnancy outcome. Examples of collective measures in the field of preconception care are rubella vaccination, iodisation of salt, radiological protection and education campaigns on the use of folic acid.

Food, drink, tobacco and other recreational drugs

A healthy, varied diet is important for everyone, and therefore also for people who wish to have a child. A healthy diet is, to a large extent, also sufficient to meet a woman's needs during early pregnancy. However, certain nutrients are already particularly important before conception. It is, for example, important to begin taking folic acid supplements (0.4 mg per day) at least four weeks before the planned conception in order to reduce the risk of having a child with a neural tube defect. Furthermore, the level of vitamin D in the body needs to be adequate.
Vitamin D supplementation is recommended, especially for women with little exposure to sunlight or who have a very dark skin. Finally, women wishing to become pregnant are advised to refrain from eating liver products in order to avoid an excess of vitamin A. Parents-to-be are best advised to abstain from of all recreational drugs. Tobacco and alcohol have been shown to have adverse effects both on fertility and on the unborn child. The use of hallucinogenic drugs is also inadvisable.

Working conditions

Exposure to high concentrations of chemical agents is detrimental to the health of all people. This is, however, especially relevant to people who would like to have a child and to pregnant women, because of the possible adverse effects on the unborn child. There are indications that exposure to high concentrations of such compounds as pesticides, solvents and cytostatics is associated with an increased risk of miscarriage and congenital abnormalities. Thusfar no indications have been found suggesting adverse effects of preconception exposure to such physical factors as low dosages of ionising radiation and noise and to other factors such as shift work on pregnancy outcomes. Stress before conception, however, can be harmful. The Occupational Health and Safety Act (*Arbowet*) already includes maximum exposure levels for chemical and physical factors and rules governing shiftwork for pregnant women. Compliance with the occupational health and safety regulations (protective clothing, extractor systems) should keep exposure to both chemicals and physical factors within safe limits.

Illness and medication

During every preconception consultation it should be investigated whether either of the future parents has – or is at risk of developing – an illness that might affect the pregnancy, or vice versa. As far as infectious diseases are concerned, rubella (‘German measles’) vaccination status is particularly important. If necessary, booster vaccinations can be given prior to conception. Pre-existing sexually transmissible diseases must be treated prior to conception. In the case of HIV-seropositive individuals, it will be necessary to discuss medication policy.
It is important that women with diabetes should have their blood-sugar levels well under control in advance of conception. Tight glycaemic control has been shown to result in better pregnancy outcomes, in terms of fewer complications and fewer congenital abnormalities. In the case of epilepsy, it is important to switch to monotherapy (if possible) or, if the woman is episode-free, perhaps even to phase out medication completely. This reduces the risk of congenital abnormalities. As far as the use of other medicines is concerned, it will be necessary to consider (on an individual basis and always under the supervision of a doctor or pharmacist) whether medication may possibly be harmful and, if this is the case, to adjust the dosage or, where possible, phase it out. Other health related factors with an adverse effect on pregnancy outcomes are obesity, anorexia and a relatively high paternal of maternal age.

Genetic factors

Preconceptional genetic counselling will in the first instance require a proper personal and family history, followed – if necessary – by referral to a clinical genetics centre. The aim of preconception counselling here is to extend the range of options available to individuals with an unfavourable genetic background and to give them more time to consider carrier screening and/or antenatal screening or the consequences of opting for (or against) pregnancy.
The advisory report takes a closer look at carrier screening for cystic fibrosis and haemoglobinopathies, since these genetic disorders are relatively common among various population groups in the Netherlands. It would be advisable to carry out a study to further explore the desirability and efficiency of general carrier screening for these disorders.

Ethical and legal matters

Preconception care can contribute to two values which are especially relevant to (future) parents: firstly, the health and well being of the child and its mother and secondly, the freedom to have children. The broad character of this type of care raises a variety of ethical and legal issues. Some ethical and legal questions are difficult to answer at this stage. One such example is the conflict between the desire to provide people with the best possible information about lifestyle and health and their right “not to know” everything (e.g. about the possible presence of a genetic disorder). Preconception care programmes should therefore be regularly evaluated, taking these possible consequences into account, e.g. in conjunction with research into the health effects of preconception care. A number of recommendations are made with a view to ensuring the careful delivery of preconception care (e.g. adopting a phased approach to the provision of information and making a clear distinction between advice that is aimed at modifying behaviour in cases where risks can be influenced and non-directive information aimed at increasing reproductive autonomy where they cannot). As far as the legal aspects are concerned, it should be pointed out that the existing statutory framework set out in the WGBO [Medical Treatment Agreement Act], WBO [Population Screening Act] and WMO [Medical Research Involving Human Subjects Act] and in the provisions of the Constitution with regard to self-determination, privacy and public health is fully applicable to preconception care.

Preconception care programme

Many of the scientific insights discussed in this advisory report are already also being communicated to prospective parents in the form of antenatal education. However, it would be better if most of the information were provided prior to conception, since this would offer greater health benefits.
The Health Council therefore advises the Minister to set up a centrally coordinated programme of preconception care, pointing out that this approach will reach the greatest number of parents-to-be. This strategy will also create the most favourable conditions for monitoring the effectiveness, efficiency and social consequence of this care programme. Furthermore, the various components of the programme (advice and interventions relating to food, drink, tobacco and other recreational drugs, working conditions, illness and the use of medicines and genetic aspects) should not be provided as separate elements but as an integrated healthcare concept. A sound knowledge infrastructure is also crucially important. The Committee urges that preconception care should be enshrined in medical guidelines. It also believes that the professional groups concerned will require supplementary training and recommends that a proper database should be established and a communications strategy should be developed in order to provide information to the target group. The organisation of preconception care will necessitate choices as to which professional groups are to deliver the general, individual preconception care. It may be possible to consider this question at regional level. Furthermore, the Committee recommends central governance with regard to monitoring, quality assurance.

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Preparing for Life
is a unique joint venture.
It will endeavour
to prevent some of Life's problems
before they begin, rather than try
to diminish their consequences after they arise.

Preparing for life

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