

## *News / Berichten*

### *In Memoriam*

#### **Els van Dongen (1946-2009)**

In the evening of 4th February 2009, Els van Dongen, anthropologist, colleague and editor of this journal, died at the age of 62. Her death came after a long and painful sickness, a period of hope and desperation, of gratefulness for a rich life mixed with stubborn resistance to the unfairness of that same life.



Els was a gifted anthropologist and an unusual colleague. Students loved her teaching, original, sharp, concerned and full of entertainment. Colleagues admired her for her unbridled energy and productivity and her many talents. She was fast in everything she undertook and impatient if things went too slowly. She deeply disliked bureaucracy and its meetings.

Her anthropological life started late, at the age of 35. She first trained as primary school teacher, during which time she met her husband Leo Hulshof. From 1968 till 1978 she taught in two primary schools in the proximity of their beautiful house in the rural south of the Netherlands, near the Belgian border. In 1978 she decided to study geography. During that course she discovered anthropology, which she liked instantly. In 1982 she decided to join the new part-time evening course anthropology at the University of Utrecht. She combined the role of student with the care of her family. She completed her master's 'cum laude' in 1988 with a thesis on the semiotic approach in the study of illness [1988].\* That approach revealed her later interest in illness as a social event and a metaphor of conflict.

Six years later, in 1994, she defended her PhD thesis based on conversations with psychotic people in a psychiatric hospital. The title of her thesis *Zwerfers, knutselaars, strateges* (Tramps, handymen, strategists) betrayed her aversion to psychiatric labels: [1994a]. She regarded the people she met in her research first of all as people out of tune with the 'normal' society, but gifted with extraordinary skills and ideas. I am sure that she experienced 'kinship' with them in their common 'unusualness'. Provocative also was the quote from John L. Caughey that she chose as device for her book:

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\* Years between square brackets refer to the publications listed at the end of the obituary.

“‘Schizophrenic’ is perhaps best kept in its traditional sense, as a pejorative label for deviants whose visions we do not like.” A few years later she would write that ‘madness’ showed: “that otherness is present in all of us. The otherness we fear” [2002b: 10].

In her book, which ten years later was published in a slightly revised English version [2004a], she sought to describe and understand how psychiatric patients experienced their world. She did so from the patient’s point of view, focusing on the fears and hopes that characterise the life in a clinical mental ward. Dilemmas in that life are: How to express subjectivity in an atmosphere designed to restrain demonstrative emotion? And how to maintain personal integrity in a completely ordered regime? She portrayed the psychiatric patients as ‘wanderers’ – homeless people, as it were – in an alien and hostile country, creating a ‘bricolage’ reality from materials at hand. Although she often positioned the therapists and psychiatrists as representatives of an oppressive regime, she did not doubt *their* integrity either.

In 1996 she joined the staff of the Medical Anthropology Unit at the University of Amsterdam and began to play her key-role as teacher and researcher in our team. She taught both general courses in anthropology and specific medical anthropology modules on themes such as ‘anthropology and psychiatry’, ‘anthropology and chronic illness’ and ‘medical anthropological ethnography in Europe’.

She published a collection of six narratives by people she met in the closed wards of the mental hospital during her PhD research. The personal stories are alternated by her observations and comments. The book, she wrote in her prologue, was her debt to these people: “I became indebted because the people shared with me what they had: their stories and (part of) their lives” [2002b: 8]. A little further she reflects: “When I went into the hospital, my aim was to study how people deal with mental illness and how mental illness could be understood from the perspective of the people themselves. Now I must admit that madness taught me more about the power of culture and the power of people than about madness” [2002b: 9].

The power of culture... In 2000 she co-edited a volume with contributions about the way Europe treated migrants in need of health care [2000]. A central theme in that volume is exclusion. It proved a recurrent theme in all her work: exclusion and marginalization of ‘others’, such as psychiatric patients, migrant, refugees, victims of violence and older people.

When she turned her attention to older people in South Africa, she came home with touching stories about the beauty and warmth of old age but also with horrifying data of older people being abused and maltreated by their own children and grandchildren. In one article [2005a] she spoke of ‘social gerontocide’. Invisible dramas unfold in poor households where the young generation despise and reject their older relatives for their passive role in the Apartheid era and try to ‘kill’ them socially. But, she stressed, the older people are not helpless victims. They fight back and develop strategies to survive.

Research among older people drew her attention to remembrance. Being old consists of having many memories. Rejecting or silencing those memories, however, implies a rejection of the older people themselves. “It is almost as if the past never happened,” one person tells her. In one of her last published articles [2008a] she quotes

a common saying of the young silencing the old: "That was your time... This time is ours!" In other words: Shut up. The 'culture of silence' in which they were forced to live during Apartheid is thus prolonged into the post-Apartheid era. That awareness of muted memories inspired her and Monica Ferreira, with whom she collaborated throughout the South Africa years, to bring out a collection of 'untold stories' to give voice to the lives of older people in the new South African society [2004b].

Her last major publications were two edited books, one about lying and concealment in medical settings and one about distance and proximity during illness. The former, co-edited with her long-time friend and colleague Sylvie Fainzang, argued that lying is a way of dealing with major crises that people encounter, particularly during illness [2005b]. The theme connects with ideas she has been airing from the very beginning: health problems are not only about health; they are linked to shame, exclusion, suffering and social violence. Lying in such circumstances may be the most effective medicine to restore the damage. But lying is mutual; those with power in medical contexts may exploit the lie as well, to maintain their position in the medical hegemony.

*Facing distress* [2007], co-edited with Ruth Kutalek, brought together papers of a conference of the European Association of Social Anthropology in Vienna. Distance and proximity constitute the ambiguity of the illness experience. On the one hand, illness leads to loss of independence and need of help and care by others; on the other hand, illness makes one lonely as it isolates the patient from normal social encounters and may scare others away. The pain of the sick body will thus be aggravated or replaced by the distress of ostracism.

In 1998 Els and I organized the first conference on 'Medical Anthropology at Home' (MAAH). For Els doing fieldwork 'at home' was a personal experience. For about ten years she had been doing research 'around the corner' in a psychiatric hospital. For me, it was – and remained – mainly a dream. For both of us it was an attempt to contribute to the de-exoticisation of (medical) anthropology. The theme and format (small-scale / intensive discussions) proved successful and since 1998 the MAAH conference has been held every second year, in The Netherlands, Spain, Italy, Finland and Denmark. Els, Sylvie Fainzang and Josep Comelles, became the driving forces. Els co-edited two voluminous special issues with conference proceedings [2001, 2002a] and remained active as long as she could. She wrote a paper [2008b] for the last conference in Denmark focusing on her personal sickness and suffering, but was unable to present it. We discussed her moving self-reflection in her absence.

In 1990 Els published her first article in *Medische Antropologie*. She described the social meaning of medicines in the psychiatric ward where she did her research. The medicines, she wrote, had a binding as well as an oppressive effect in the interaction between patients and staff. Relations between these two parties had the character of a combat in which medicines (taken or refused) replaced words. [1990] The article became a key-text in our work on 'pharmaceutical anthropology'.

In 1994 she helped as guest editor to make a special issue about *Zintuigen* (The Senses) and in that same year she joined the team of editors. She kept that position till the end of her life. *Medische Antropologie* has been the main outlet for her ideas on health, culture and violence, certainly in the first decade of her career. She wrote

eighteen articles and comments and an uncounted number of book reviews for this journal and (co-)edited five special issues on 'the senses' [1994b], 'older people, well-being and care' [1997], 'shit, culture and well-being' [1999], 'medical technology and the body' [2002c] and 'violence and human rights' [2005c]. We, the editors, will miss her fast and sharp judgment in the evaluation of manuscripts, her invaluable editorial suggestions to the authors and her cheerful directness during our discussions. Another journal favourite journal for her was *Anthropology & Medicine*, in which she published about the creation of cultural difference, lying and illness, and bodywork in nursing.

From the beginning in 1994 she has also been one of the editors of the book series 'Health, Culture and Society' which has brought out sixteen titles so far.

Els was a person with many talents. She took lessons in drawing and painting and produced beautiful canvasses with symbolic objects and portraits of relatives, friends, and people she met during fieldwork. Many of her productions can still be viewed on her website. She was also a filmmaker and photographer. The topics she chose for her photographs and films were sometimes from her anthropological research but often focused also on other things such as nature, everyday life and unexpected details such as the movements of hands during a conference.

Els has lived a very full life and accomplished more than most of us will be able to achieve in a life twice as long as hers. Even so, she was not always a happy scholar, perhaps feeling that her close colleagues did not fully understand or appreciate what she was doing. Close colleagues are sometimes more distant than those who are far away. Nevertheless, in this space, she carried on with her own strong and positive energy, becoming a popular guest lecturer in universities abroad and serving on various international scientific committees. When her sickness grew more serious, about two months before her death, we decided to make a book of friends for her. Thirty-eight people, colleagues from Amsterdam, from other Dutch universities and from abroad, plus students and friends contributed brief essays (and one poem) that dealt with the themes that had been prominent during her academic life. They focused on people who are excluded or marginalised, because of their age, their illness, their 'madness' or because they are living in violent circumstances. Other contributions were about people who are oppressed because they do not fit in the dominant discourse: people with HIV/AIDS, victims of (sexual) violence, refugees and migrants.

The title of the book 'Theory and Action,' was the name of a famous core module that Els taught in the Master's of Medical Anthropology and Sociology. In one of her papers she stressed that theory and action are closely connected in medical anthropology. "Theory helps us to bear our ignorance of facts," she quoted George Santayana. Facts, she continued, acquire their meaning from what people do to them, in this case anthropologists and the people they are working with. Theory provides a way of finding pertinent meanings and making intelligent interpretations that open the door to relevant action. She then cited the famous line from Kurt Lewin that there is nothing so practical as a good theory. A good theory is practical because it enhances understanding and produces the questions that really matter in medical anthropological research.

In her module, Els discussed with the students that problems of ill-health and suffering should be regarded in their historical, political and economic contexts and how larger social and political forces shape relations and actions and cultural imagination at the local level. The necessary – but often difficult – cooperation between anthropology and health workers received special attention. Questions that were addressed during the course included: Why do we need theory? Which theories are relevant? How can we link macro, meso en micro theories with practical work?

‘Theory and Action’ constitutes both medical anthropology’s ambition and its weakness. The frequent criticism that medical anthropology receives from those who work in the heat of the day confirms that, unfortunately, much academic work remains largely or totally useless to ‘actors’ in health care. Nearly every contributor in the book struggled in one way or the other with this dilemma and with the challenge of proving the practical relevance of theory.

When her condition became critical, we decided to tell her about the book and gave her the list of authors and the titles of their contributions. She was overwhelmed and deeply moved when she saw the list of so many friends. She gave us one of her paintings for the cover of the book and allowed us to include one of her last essays that dealt with her own illness and the way people express their connectedness in times of suffering and uncertainty [2009]. Four weeks later we brought the book. I held a short speech and she responded directly and with humour. She was almost too weak to open the paper wrapped around the book. We drank a glass of wine and had a lovely lunch while she observed us from the sofa. She read the essays and reacted personally to many of the authors. Ten days later she died. On the 9th February we said farewell to her in a ceremony full of music and words of comfort.

Sjaak van der Geest



*‘Older woman in mental hospital’ by Els van Dongen*

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### *Els van Dongen, docent en begeleider*

“We are all orphans now,” schreef Amina, een van de oud-studenten van Els in haar e-mail toen ze het bericht ontving dat Els was overleden. Het klinkt misschien wat pathetisch, maar op professioneel vlak voel ik me ook een beetje zo. Voor mij en vele andere studenten heeft Els een bepalende invloed gehad. Haar colleges waren zeer bijzonder. Het feit dat de laatste onderwijsmodule die ze heeft gegeven door studenten met een 10 werd beoordeeld, zegt voldoende. Ze gaf eigenlijk geen colleges, ze vertelde verhalen op een gepassioneerde wijze. En wij studenten hingen altijd aan haar lippen. De associatieve manier van denken en praten, haar belezenheid en het gemak waarmee ze in haar verhalen theoretische patronen over het leven van alledag kon leggen was uitzonderlijk. Ze was altijd zeer goed voorbereid. Al haar verhalen waren afgewogen en uitgeschreven. De passie waarmee ze vertelde was aanstekelijk. Ze heeft mij richting gegeven aan mijn denken en werken. Dit geldt ook voor vele andere studenten. Door haar is antropologie voor mij geen vak, maar een manier van leven geworden.

Ze begeleidde mij met mijn afstudeerscriptie. Ze was zorgzaam, bijna moederlijk af en toe. Gaf me een knuffel toen ik vertrok voor mijn veldwerk en in een van haar e-mails uitte ze haar zorg over dat ik te hard werkte. Ze schreef: “Ook genieten hoor! Niet alleen denken maar ook doen en pas goed op jezelf.” Maar thuis gekomen was het afgelopen met haar stimulans om te genieten. Ze eiste veel van ons studenten. Toen ik met enige trots het eerste hoofdstuk van mijn afstudeerscriptie had ingeleverd zei ze tijdens de bespreking, dat ik me er te simpel van afmaakte en me te veel op geplaveide paden begaf. Dat kon niet. “Kruip maar eens door de bramenstruiken”, zei ze en met die opmerking stond ik volkomen verward weer buiten de deur. Het kostte me altijd enige tijd dit soort cryptische opmerkingen van haar handen en voeten te geven, maar uiteindelijk bracht het me verder dan ik zelf ooit gedacht had.

Ze was ook mijn co-promotor. Ik had haar daarvoor gevraagd vanwege haar dwarse en creatieve geest. En ik werd niet teleurgesteld. Altijd weer kwam ze met bijzondere inzichten en suggesties.

In de afgelopen jaren is mijn relatie met haar veel intenser en persoonlijker geworden. In het najaar 2007 zouden we gaan vieren dat het erop leek dat ze de kanker had overwonnen. We zouden gaan wandelen en champagne drinken op het strand. We hadden al een datum: maandag 15 oktober om 11.00 's ochtends. Vroeg voor champagne, maar het maakte niet uit want we hadden reden genoeg om de dag in gepaste dronkenschap door te brengen. Een paar dagen daarvoor belde ze af. Ze had erg veel pijn en was zeer ongerust. Tot mijn grote verdriet is voor champagne drinken nooit meer een reden geweest.

Ondanks alle operaties, zorgen, verdriet en pijn heeft ze me tot aan enkele maanden voor haar overlijden nog met mijn proefschrift begeleid. Ik kan niet goed onder woorden brengen wat die inzet voor me betekent.

Beiden hadden wij zo gehoopt dat ze mijn rite de passage, het verdedigen van mijn proefschrift, nog mee zou kunnen maken. Het mocht niet zo zijn.



Ik zal het nu, net als de andere oud studenten, zonder haar moeten doen, als een soort weeskind, maar wel met onze bagage gevuld met visies, ideeën en ontzuhtende opmerkingen van Els. Ze heeft voor de rest van mijn leven een plek in mijn hart én in hoofd veroverd. Ik hoop dat ze me zo blijvend van het geplaveide pad houdt.

Marian Tankink\*

### *In Memoriam*

#### **Bas Treffers 'de man zonder voetstappen' (1944-2008)**

Bas Treffers stoelroller ten gevolge van polio heeft zich meer dan dertig jaar met humor en constructieve boosheid regionaal en (inter)nationaal ingezet voor een betere positie van mensen met een beperking. Zo was Bas bestuurslid van de Gehandicaptenraad, de voorloper van de Chronisch zieken en Gehandicapten Raad en medeoprichter en vice-voorzitter van het European Disability Forum (EDF) alwaar hij 'Toegankelijkheid' in zijn portefeuille had. Hij heeft onder andere bijgedragen aan de acceptatie van en certificering van toegankelijkheidsnormen en de instelling van de leerstoel Europees Gehandicaptenrecht.

Behalve belangenbehartiger was Bas vader, echtgenoot, schrijver, dichter en Huisenaar. Ik kende Bas in eerste instantie als straatgenoot en vader van een klasgenoot. Als klein meisje vond ik het wel handig dat ik me aan zijn rolstoel kon vastgrijpen en mijn hoofd niet in mijn nek hoefde te leggen om hem aan te kunnen kijken (een pre als je, zoals ik, een evenwichtsstoornis hebt). Pas vele jaren later spraken we elkaar over een gemeenschappelijke interesse: het gebrek aan toegankelijkheid van medische voorzieningen en procedures. Het komt nog steeds voor dat patiënten met makke niet volledig onderzocht worden omdat de gangbare medische procedures en voorzieningen, zoals behandelafels, niet ingesteld zijn op deze 'vaste klanten'. Bas is 24 december 2008 voortijdig overleden. Hij zal gemist worden niet alleen om de persoon die hij was maar ook omdat zijn werk nog lang niet af is.

Karen Mogendorff

### *In Memoriam*

#### **Cecil G. Helman (1944-2009)**

Dr Cecil Helman, medical anthropologist and author of 'Culture, Health & Illness', died on Monday 16 June at the age of 65. A few months ago he was diagnosed with

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\* Bewerking van toespraak tijdens afscheidsdienst op 9 februari 2009.



motor neurone disease, which led to increasing speech debility and swallowing problems. For the last few months he was unable to speak and wrote on a pad. He had just retired as professor of Medical Anthropology at Brunel University, West London and senior lecturer at University College London, Medical School.

Cecil Helman was born in Cape Town, South Africa into a medical family, and qualified as a doctor at the University of Cape Town. He left South Africa because of the *apartheid* system, and then studied social anthropology at University College London. Over the years he had combined several different careers into a creative synthesis: family doctor, anthropologist, university lecturer, writer and poet.

After a brief spell as a ship's doctor in the Mediterranean, he worked as a family doctor for 27 years for the National Health Service, in an around London, combining his clinical practice with an academic career. He was an international expert on medical anthropology – the cross-cultural study of health, illness, and medical care – and on different forms of health care and healing. He did research on primary health care systems, and on traditional healers, in South Africa, Brazil, and elsewhere.

He lectured to medical students, doctors, and nurses and taught courses on cross-cultural health care. He was particularly interested in the humanistic side of medicine – especially the role of stories and narratives in medical care, and what they reveal about the inner worlds of both doctor and patient. Among his other interests were the role of metaphors and symbols in our understanding of the human body, in both illness and health; and what the Western industrialized world could learn from the healing systems of more traditional societies, when dealing with different aspects of human suffering.

His textbook '*Culture, Health and Illness*' (first published in 1984; now in its 5th edition) has been translated into seven languages and is being used in more than 40 countries, including in over 120 universities, medical schools and nursing colleges. Cecil Helman is well-known to students of medical anthropology in the Netherlands as his book has been used for more than twenty years in courses at the University of Amsterdam. Primarily written for health professionals, it is without doubt the most complete overview of medical anthropology. For anthropologists it contains perhaps insufficient theoretical discussion from a general cultural anthropological perspective, but as a textbook it offers a wealth of information, a precious overview and abundant suggestions for further reading.

On the literary side, Cecil Helman published both non-fiction and fiction, including a memoir '*Suburban Shaman: Tales from Medicine's Frontline*', a book of essays about the body, an anthology of stories about doctors and patients, a novella, and several books of prose poems. His poetry and other writings have appeared in many anthologies and literary journals.

We have lost a creative and inspiring colleague but his solid academic and sparkling literary work will be with us for many more years.

Sjaak van der Geest\*

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\* Part of this text has been adjusted from Cecil Helman's personal website.

### *Invitation and call for papers*

#### **Symposium 'Care & Health Care', 18 December 2009 University of Amsterdam**

The annual symposium of the journal *Medische Antropologie* (18 December 2009) will have as its theme 'Care & Health Care'. The editors invite you to contribute a paper on this theme. An invitational article by Arthur Kleinman and Sjaak van der Geest 'Care in health care: Remaking the moral world of medicine' appears in this June issue of the journal. The article that intends to motivate and encourage participation and writing of papers can be sent to paper writers on their request. At the end of this call you will find a brief sketch of the theme.

The symposium will take place at the University of Amsterdam. Venue is Het Spinhuis, Oudezijds Achterwal 185, Amsterdam. The symposium will consist of thematic discussions based on submitted papers of the participants. During the symposium there will be no formal presentation of papers, but only a short introduction to be followed by a discussion.

A selection of the symposium papers will be published in the summer 2010 issue of *Medische Antropologie*. Registration for the symposium is possible until 30 November via the website of Medical Anthropology & Sociology Unit [www.medical-anthropology.nl](http://www.medical-anthropology.nl) under Agenda: 'Symposium Care & Health Care'; click: Register, fill the form and submit. Participation is limited to 35 people, and registration will be processed in order of arrival. The symposium fee is € 25 to be paid at the symposium. Participants will be given access to all papers no later than a week in advance of the symposium. They are expected to read all the papers in preparation of the symposium.

Those who are interested in submitting a paper should provide a title plus brief abstract together with their registration, before 1 November 2009. The complete paper should be sent as an attachment per email to: Janus Oomen, [h.a.p.c.oomen@uva.nl](mailto:h.a.p.c.oomen@uva.nl) before November 27, 2008. Papers should be in English. Drafts and work in progress are welcome.

*Authors are invited to consider the following questions:*

- What constitutes 'good care' in a given social or cultural situation?
- Are medicine and care compatible?
- Is there enough 'time' for care in today's health care system?
- To what extent does the concept of care vary in different cultural contexts?
- How can we understand the gender-based differences in care perception and practice?
- Is care related to reciprocity?
- Which conditions call for care and which ones do not?

- How does the concept of care evolve in relation to the development of medical technology?
- How does care evolve in conditions of radical cultural change and acculturation, e.g. in the life of migrants?
- What is the economic basis for caregiving?
- What explains the low social status of caregiving as a profession?
- What policy could enhance the quality of care?