
Wientjens

2:20pm Sep 3, 2014

1

Will be the discussion only oriented on the opinions of people who are giving education ? What about the opinons of people with diabetes ? I am 77 years young; having insulin punp and also CGM.
KR Wim Wientjens

mariliruiz

12:14am Sep 4, 2014

6

thanks Wim, of course in this place you can give your opinions, your suggestions and experience in pumps, We have a group of patients in pumps in our hospital and we have a meeting every month to share tips and ideas about the use and all about pumps, it is the best way to learn with pears, both to health professionals and patients, so you can share your experience! For example, what myths do you have before using pump, that then you change your mind when begin using it?

Fabiola Spagnuolo

1:20am Sep 5, 2014

#11

Hi, fortunately in Argentina health insurance give us the pump for free. I've been using it now for more than two and a half years, and I can't believe how my life has change for good!!! I used to be in an intensificate insulin plan, with Lantus and multiple shots with Humalog, now the plan is basically the same, but with one needle every three days!!! My levels have improve dramatically, my Hb1c is now 5.7%!!! And what have surprised me the most, was seeing small kids of 4 or 5 years old, using their pumps and counting carbs naturally, not feeling the pump as a charge at all. I truly recomend it with all my heart!!! Thank you dr. Mariliruiz, I've been in Villa Giardino at the FAD join and your conference has been fantastic!!!

mariliruiz

5:16pm Sep 6, 2014

#12

thanks Fabiola for your comments! can you tell what where your fears before using it and what are the more important changes you find using the pump in your daily life?

Fabiola Spagnuolo

4:42pm Sep 7, 2014

#16

My fears... Well I'm kinda fearless... But I thought it would be difficult to have it attached to my belly, that it could disconnect itself... Actually I remember I didn't nearly sleep that very first night!!! But now I never forget pre meals controls, (and the alarm never lets me forget de post meals controls), it's easier to determine how many units I have to use to correct a meal (I give all the data to the glucometer and he kindly gives me his advice about the subject), I don't have to carry so many things as before (two or three insuline pens, in case one were almost finished, cotton, alcohol, needles, the glucometer, etc). Now I carry a syringe, just in case there's a problem with my pump, to get a solution until I arrive home, that I put in my make up bag, the glucometer and voilà!!! I'm ready to go!!! And it's easier to see how am I managing my metabolic control with the Objective opción, which shows in a graphic my values in different moments of the day, and even in the last 90 days, that allows me to rank how my Hb1c will be... It's unnoticeable, I don't have to give explanations in some environments (I never injected myself in the bathroom because of the possibility of infections, so I was forced to say "it's ok, I'm diabetic, I'm not doing drugs..." jajaja. For me, for the part of my life that's related to diabetes (because I don't suffer diabetes, I'm the owner of my diabetes), has been a dramatic change, there's a before and an after!

JildeIDF

2:38pm Sep 3, 2014

#2

Dear Wim,

Thank you for your question!

The target audience of D-NET is health professionals working in diabetes and diabetes education and that is why the introductions of the discussions are oriented on diabetes educators.

However, the opinions and experiences of people with diabetes are very valuable for diabetes educators and therefore you are more than welcome to share your experiences in this discussion and other discussions. Maybe you have some tips and tricks for diabetes educators on how to educate a person with diabetes on the use of an insulin pump.

Looking forward to hearing from you!

Kind regards,

Jilde

Polis

3:01pm Sep 3, 2014

#3

The bigger barrier that i find is that is a non-stop education prosedure.I mean you cant learn and educate about the pump and then you just stop.You must have update your knowlegde about the pumps and how they work,because technology improves through time and with fast rate and we have to be able to follow this rythm.

lufuno obey

5:55pm Sep 3, 2014

#4

Insulin pumps is very but it's too expensive

lufuno obey

5:57pm Sep 3, 2014

#5

Medical aid do not pay in South Africa, you buy it for yourself

mariliruiz

12:20am Sep 4, 2014

#7

I agree Lufuno . In a lot of countries the pump is expensive and not available for everybody...but in another countries, although there are possibilities to use it, a lot of doctors have fears about using technology and some patients have myths about using this type of therapeutic tool , for example, how manage to carry in the body, etc, problems that disappear when quality of life increases and they realize that they dont have hipoglycemia or they can have more freedom.

Liz Knight

1:34am Sep 4, 2014

#8

Hi I am a diabetes educator in Australia and am just about to start helping people with pumps as I just completed the training. There are not that many people with diabetes using pumps in my area and I am excited to change that. I have found using the meters which calculate correction doses & meal boluses based on TDD of insulin & 100 / 500 rule a really great step off into pumps - they are like pumps with out the pump!! Cost is a problem in Australia although private health will cover it you still have to pay to be a member of a fund. Also in rural areas (where I am) we don't have specialist doctor support & GPs are not really confident in pumps so I am looking for a way to work remotely in conjunction with a doctor prepared to support patients in our area.

Debbie Scadden

6:21am Sep 4, 2014

#9

Hello all, I am also a Credentialed Diabetes Educator Registered Nurse - Clinical Nurse Consultant. I live in a rural area, we have 5 staff including myself to cover 33 hospitals and community health centres. I cover the region at strategic level and the other 4 provide face to face education. We have no Endocrinologist services at any hospitals. My concern is the resources, time, support required when we care for birth to death range of pre diabetes, Type 2, Type 1, gestational diabetes, diabetes in pregnancy to the whole community covering high incidence Aboriginal and Torres Strait Islander population, subcontinent Indian people along with a growing multicultural population layered with epidemic level of obesity. Client load is more like 5,000 clients for each staff member. Pumps are for a small number of people here unfortunately, have to do start up in metropolitan city areas and then the client comes back to the rural area.....

Wientjens

1:37pm Sep 4, 2014

#10

Dear Jilde/Mariliruiz/Debbie/Liz/Lufuno/Polis and I hope many others.

My opinions are based on a few principles.

- 1) I am very happy that IDF is using three standards of care: a) comprehensive care b) standard care c) minimal care. Of course, we all hope that everybody in the world has the same care (following one WHO-standard) but unfortunately this is not realistic.
- 2) Care must be "in concordance" with the patient. So, care must not be dominated by "in compliance", in which there is a tyranny of rules and guidelines.
- 3) People with diabetes must not hide their diabetes, but must come out with their diabetes. Only

then there is the possibility of good discussions, of good education, of avoiding discrimination in their society because of having diabetes.

Mariliruiz, my myth before starting with the insulin pump was thinking that it would be for me the start of the artificial pancreas. But soon, the feeling was being very disappointed. In reality for me it was only the beginning of a new method to give me the insulin, after I gave me already around 70.000 insulin injections in my body. Since I studied biochemistry and since I was in my professional career managing director of an applied scientific research institute, I did not have problems in handling the pump. Also, since in my country (The Netherlands), the support by the company of the pump itself and of the diabetes nurses and of the pharmacists are excellent. Since The Netherlands is also very multicultural the educational support is rather good, also when there are for instance recall actions.

Because of my many complications of diabetes, I got a few years after the beginning of the pump, also a sensor for the CGM, the continuous glucose monitoring. Also the educational support for this device was again good, like mentioned before about the pump. Of course, I am still looking to the coming new technologies, like the sensor with ambulatory glucose profile (AGP) monitoring. Will I see the myth in my last years ?

I like to mention here that, after my retirement 15 years ago, of my professional career, I was asked to write down my experiences regarding living with diabetes during such long period. I did it and that book was printed in Dutch (10,000 copies). My conditions were : written as volunteer, nobody was allowed to change any word, I did not want to receive any penny and the printed copies of the book, was free of any charge available for people with diabetes and for health care providers in The Netherlands. When all printed copies (10.000) were given away, a second edition appeared, extended now with my international experiences, and as an ebook. Under the same conditions as mentioned before. So, free of any charge to download by everybody. Rather soon it was available not only in Dutch, but also translated in English and in Russian. At the end of this year it will be available in Arabic. Everything with the same conditions as mentioned before. And, I am very happy that several items of the book will be used in education projects on schools in Egypt at the end of this year. Title "Diabetes...So what?" with serious answers on this question. See www.wimwientjens.com
Kind regards, Wim

mariliruiz

5:23pm Sep 6, 2014

#13

thanks a lot Wim for your comments! and congratulations for your book and your share of experiences! it is very interesting the myth that the pump is an artificial pancreas, we are waiting for this and for the technological advances but for now this tool allows a lot of changes but the use depends on the person who uses it and his education. Thats why it is very important the education of the patient and the education of the health care providers.... Can you share with us Wim your experience using the sensor? Do you have important differences between interstitial glucose and plasmatic glucose? Do you have differences the first days of the sensor or after change it? In which areas of the body you prefer using it? thanks!

Buyelwa

9:09pm Sep 6, 2014

#14

It is extremely important for health providers to be well informed and stay updated about how insulin pumps work. Listening with interest to the patient's feedback helps us learn what is not written in the books. In developing countries as Lufuno has mentioned, insulin pumps are used by few individuals as they are not freely available. Thanks Maria for leading this important topic, we will learn a lot from it.

mariliruiz

7:43pm Sep 8, 2014

#20

thanks Buyelwa! really patients feedback helps a lot!!! warm regards

Wientjens

10:44pm Sep 6, 2014

#15

I fix the sensor in my belly, Maria. In principle the combination of my pump and my sensor can already act now as an artificial pancreas, but product responsibility is still prohibiting it. Indeed there are of course differences between parameters you are mentioning, but they are of minor importance compared with the fluctuations of my body and my activities. I am still not a robot. Happy that you are stressing not only the education of patients, but also of the health care providers. Kind regards,
Wim

Wientjens

4:59pm Sep 7, 2014

#17

Great Fabiola. May I ask how young you are?

Fabiola Spagnuolo

6:22pm Sep 7, 2014

#18

I'm 45, diagnosed with type 1 diabetes 15 years ago.

Wientjens

6:49pm Sep 7, 2014

#19

Excellent. I like your enthusiasm and your statement 'I am not suffering, I am just the owner'. And the world is changing so tremendously. Do you know that In The Netherlands many years ago the needles for people with diabetes were not free of charge, but that people who were injecting themselves with drugs got free of charge needles, just because to avoid that they would get infections by using old needles getting from other drugs users. Injection / infection. Just one letter.
Wim

mariliruiz

7:53pm Sep 8, 2014

#21

thanks a lot Fabiola and Wim for your feedback, it helps a lot to see what are the real feelings of PWD and also to understand what an educator has to know before helping people to manage a pump.... The ADA suggests that success in using pumps is: Multiple ranges of basal to 0.025 u / hour Use types of bowling combined Calculation of bolus according to different strategies (CH, glycemia, IC ratio, sensitivity factor, DIA (dose of insulin action) Occlusion alarms Modify according to different situations Anticipating actions (exercise, fasting) No return to dependent patient bolus calculator and most frequent problems Reacting to the number without analyzing patterns Fix between meals (not to analyze the pattern) NO Download data to study patterns and review Baseline test and IC ratio increase the dose or down according to fears of hyper or hypo....

Fabiola Spagnuolo

8:25pm Sep 8, 2014

#22

Wim: It's incredible what you've done!!! I've just got the english version of your books and started reading them. I would like to have your permission to translate some parts of them to Spanish to share in my Facebook group MI DULZURA Y YO - APRENDIENDO A VIVIR CON DIABETES (My sweetness and me - Learning to live with diabetes), mentioning the source and being as close to your words as I can. I'm trying to help others in my country and some others countries all around America, sharing information and experiences, events, and everything that could help people to deal with their diabetes. It's really a sweet work, that fullfills my soul with so much love that I can't imagine my life without it. And your books are great!!! Anyways, I will like to stay in touch with you! My facebook is Fabiola Spagnuolo and my mail address fabiolaspag@hotmail.com Love from Argentina!!!

Wientjens

7:29am Sep 9, 2014

#23

Fabiola. Thanks for your nice words. After Maxima (sent to The Netherlands as queen) and the Pope (sent to Rome) Argentina is sending now you and Maria Lidia to these good IDF D-NET discussions. As soldiers in the battle field between (as I mentioned before) the "in compliance" rules and guidelines (like the ADA) and the "in concordance" with people with diabetes. Fabiola, I hope you have seen already in my experiences, how I admire the evolution and progress in the healthcare. The ebola is terrible at the moment with 2000 dead people. "But" did you read that I received the last sacraments when I was 19 years, having diabetes, astma, influenza attack, not vaccinated ? I survived, but only in The Netherlands 1900 people died that winter because of that virus. Fabiola, no problem to cite me. Conditions: - really free of charge everything; I don't want to receive any penny - mentioning from : Wim Wientjens, "Diabetes...So What?", 2nd edition, www.wimwientjens.com - translation in Spanish as good as possible; send me a copy - no commercial activities of MI DULZURA YO ... - I would like to receive some curriculum of you; are you one the Fabiola Spagnuolo's on Skype or LinkedIn ? - I am not on FaceBook; I am on LinkedIn and Skype (I am not frequently skypeing) - my email wim.wientjens@gmail.com. Let's continue these matters directly between you and me. KR Wim

viv.traynor

9:32am Sep 9, 2014

#24

Hello, I am a DSN living and working with people with diabetes in Cyprus. Pump therapy has only been used in Cyprus for the last 5 years so our experience is limited and we all, health care providers and people with diabetes, are learning together. Pumps and all consumables are provided free of charge by the national health system. People that go on the pump therapy have to meet certain criteria before they are given the pump.

I am very much interested in what Dr Maria Lidia Ruiz said ref. the monthly meetings they have in her hospital to share experiences tips etc. When we first started and we only had about 6 people on pumps we used to meet prior to Pump Clinic for half an hour and discuss different issues and experiences. Both the users and me as a healthcare professional found this very rewarding a fantastic learning experience and also such a bonding time. Unfortunately due to the increasing numbers of pump users this informal meeting was no longer possible. I have been thinking for a while in starting again such a meeting since of the original group keep telling me that they had benefited from it and would like it back. I would be grateful if people, both users and healthcare providers, can share their experiences and/or ideas how to get such a meeting started. The first time it was not planned - it just evolved. Some thoughts please on how to organise it?

Vivie

Luz

5:29pm Sep 9, 2014

#27

so that everyone can come at least every once in a while. We all sit together in a circle. Each meeting has a first part in which we do an ice breaker, that is some type of activity in which people become comfortable with each other, introduce themselves, etc., and a second part in which we play a game or discuss a topic. It's not a class but a workshop that we all build together. The lessons that we learn and the interaction is such that we've even received doctors in training more than once to listen to what patients have to teach! We understand that diabetes treatment is centered in the diabetic person, who is a fundamental part of the team around him/her. If he/she is not part of the learning process, if the lessons learnt are not taken into account, there's no possible sustainable improvement in the treatment. I hope this info helps, let us know if we can help in any other way! Best, Luz

Luz

6:32pm Sep 9, 2014

#28

sorry, here goes the 1st part of my message!

Hello everyone, my name is Luz, I've had type 1 dbt for more than 30 years and have been using a pump for around 7. I live in Argentina and work on the afore mentioned workshops together with Dr. Ruiz. Vivie, we started with the workshops around 2 years ago. They are organized by Dr. Ruiz, a diabetologist, Lic. Lando, a dietitian, and myself, who apart from being diabetic and a pump user myself am a group facilitator and diabetes educator. We plan each workshop ahead and invite people at least two weeks in advance. We also try to change the days in which we do it (sometimes on Monday, sometimes on Tuesday, etc.)

Fabiola Spagnuolo

7:11pm Sep 9, 2014

#29

That's great, Luz! That's exactly what I'm trying to do with the group a friend and I created in Facebook. Specially in some small towns when there's no way to find a health provider or a diabetes educator, helping each other on line is a way to spread good quality information and the personal touch that could turn information into educacion, and education into accion. Thank you and good luck!!!

Wientjens

10:33am Sep 9, 2014

#25

Dear Vivie, the only suggestion I can give you is try to organize such meetings together with your CDA in Cyprus. People with diabetes are everywhere very helpful to organize in their free time as volunteers. Time which healthcare providers don't have enough anymore for it. They also are giving already a lot of their free time. Would it be possible on a Saturday ? I have wonderful memories on the diabetes activities in your country. On Soteris Yiangou, Loulla Constantinides, Dina. And your willingness to co-operate with Emete Inge from the "Cyprus Turkish" Diabets Asociation. And ... how I was helped after getting a hypo during my walk alone in the UN green zone back from the occupied area. See chapter Hypo's in my "book" Fabiola is mentioning above. KR Wim

InesLando

2:27pm Sep 9, 2014

#26

Hello, I am dietitian and I work in Argentina with patients with insulin pump since 2006. I am interested in this forum. I want to know if someone has experience in fat and protein count adding in carbs count and which bolus do you suggest in this case, if its bolus extended or dual. Thanks, Inés Landó

Fabiola Spagnuolo

8:22pm Sep 9, 2014

#27

Hi Ines!!! We met in a workshop AccuCheck did last year for people with pumps. Actually I'm very interested on this subject, as I heard of it for the first time in Villa Giardino, at Marili Ruiz conference.

mariliruiz

11:55pm Sep 9, 2014

#31

Thanks FAbiola, Ines and Luz! can you also share your experiences in the spanish group? What Ines is asking for is the uses of special boluses in some special foods...first, I want to explain to the people who dont have experiences in pumps, that with the pump you have the opportunity to use 3 types of boluses (as correction and CH counting): the standard bolus, that is like the one everybody uses with insulin therapy, the extended bolus, that you can calculate to be extended in time, for example in 1 hour and that it is special for fat foods o when there is hypo before having a food, and the dual bolus, half standard, and half extended....

hazaline

11:12pm Sep 12, 2014

#32

Hi, I am a medical doctor who has just graduated. I am so glad to read the experiences of the people with insulin pump. But I wonder, there will be some patients who do not switch to insulin pump but still stick to daily multiple injections even though insulin pumps are available and free for them. According to the comments above, insulin pump looks a marvellous invention. Anyone can share me the reasons why they don't change the method?

Fabiola Spagnuolo

12:43am Sep 13, 2014

#33

Hi Hazaline! I think maybe because they think that it's difficult to operate it or programe it. It wasn't for me but I like all kind of gadgets! So it was a new one for my collection! Some other people told me that they felt the pump would be difficult to carry on their bodies. And by the other hand, there are a lot of doctors who don't prescribe the pump because they are not trained (and not interested

on being trained!!!) the same way they sometimes don't insulinize their patients because they have to explain how to apply insulin, corrections, monitoring, emergencies, and so on, and there are no diabetes educators available to do it, and they have not time enough to do it either. That really sucks! I've seen too many people with diabetes related problems because of a late insulinization (or no insulinization at all) and sometimes I wish I could turn into the Incredible Hulk to throw away their doctors!!! Hope you will become a great doctor, who really cares about people!!! Like my beloved doctor María Pia Santucci!

hazaline

10:57am Sep 13, 2014

#34

Thank you so much, Fabiola. It is very nice to hear your experiences. And thanks again for your encouragement. I am really interested in Diabetes. I would like to hear more from everyone as I believe it would help me a lot to my practice.

mariliruiz

2:20pm Sep 13, 2014

#35

Hi Fabiola and Hazaline. Great to read you! I strongly agree with Fabiola, and I think that people and doctors and all the health group must know about this kind of treatment...of course there are countries where economic causes may be important to choose one or other therapy. But for example in Japan or in Finland, there are few pwd in pumps and perhaps is for training or believes...I also continue thinking that the person who is ok in his treatment (for ex. 1 nph BT and HbA1c less than 6.5 or 7) he can continue with that and pumps can be for intensive insulin treatments that needs basal boluses treatment or in some situations (hypoglycemia unawareness, complications, variability, etc)

hazaline

5:29pm Sep 14, 2014

#36

Hi Mariliruiz. Nice to read you too. I would like to know whether the insulin pump also reduces the risk of complications in accordance with your experiences. I think there will be some healthcare professionals who hesitate or can't trust in new technology. And I heard from some people that they are afraid of the feeling that a small needle is attached to their belly all the time, and they prefer multiple daily injections despite their glycaemic control is not good. Maybe they need to be

educated more about insulin pump? or the treatment plan should be decided by them and continue multiple daily injections?