

# **SPAIN - COUNTRY REPORT 2017**

**by Cynthia Robinson**

Since my last report (on the closure of EOS in 2014), EOS has in fact continued as an information service (EOSIS), the situation being that one could not abandon either ostomates with whom we have retained contact or the information sources we have built up over 17 years. Our conscience would not allow it!

We have included in our 2017 Country Report information which, we hope, will assist the EOA Committee through the Englert Fund to progress the development of a new representative Spanish organization of ostomates.

In our 2014 Country Report we reviewed the national population statistics (per the 2010/12 general census) and noted that, out of a total population of approximately 47 million, it had been estimated that there were some 70.500 ostomates (ie. 0.15%) in Spain. That basic assessment of the proportion of ostomists in the population was that made by Professor Bienvenido in the 'Manifesto' which represented the conclusions of the National Congress of Ostomists held in Bilbao in December 2005 - to which document EOS was a signatory. The figure compares with the equivalent figures of between 2 and 4 per 1000 reported in other western countries.

The requirement for ostomy surgery can affect any person at any time in life - even babies. For statistical estimations at least therefore, if (for example) a 20-year old has had twice as many chances of it as a 10-year old, then we can compute from the general demographics the likely age distribution of ostomates:

0 - 15 yrs: 2.100 patients nationally.

16 - 44 yrs: 22.600 “ “

45 - 64 yrs: 24.000 “ “

65 and over: 22.000 “ “

Considering just the expatriate population that then stood at 2.579.000 or 5.5% of the total, it is possible to refine this data by dividing them between those of working age in the cities and countryside and the retirees on the Costas (the coastal regions).

Because of the very different lifestyles and needs of expatriate ostomates as compared to the Spanish, and the difference in age profiles between these two classes, the distinction is important:

Expatriates living in cities and inland: 1.470.000 total – weighted similarly according to age profile.

0 - 15 yrs = 63 patients.

16 - 44 yrs = 1.054 “

45 - 64 yrs = 520 “

65 and over = 116 “

Expatriates living on the Costas: 1.109.000 total – ditto.

0 - 15 yrs = 36 patients.

16 - 44 yrs = 506 “

45 - 64 yrs = 628 “

65 and over = 581 “

This shows why the Spanish ostomy associations are all city-based while EOS is kept busy here in the small but touristic port of Jávea on the famous Costa Blanca. In the general recession that followed after the census on which these figures were originally based, there was a considerable reduction in the expatriate population but it is now probably recovering - although the mix of nationalities now arriving will no doubt favour those from the Euro zone and eastwards - thus diluting the traditional dominance of Brits.

## **Organisation**

While there is no discrimination against ostomates generally, the Spanish greatly prefer to hide rather than to celebrate their life-giving condition, and are mostly known only within their families. At least outside of the main cities, membership support and participation in representative organisations is therefore insufficient for their effectiveness.

By far the largest and most successful of the Spanish associations is the Bilbao-based ARGIA who celebrated their 25th anniversary in 2012. ARGIA's original president, Professor Dr Bienvenido Sánchez, a wonderful and unique person, was responsible for the only important publication on ostomy in Spain - the Bilbao Manifesto - and this he been presented at their Congress in 2005. The signing of this document by all the known associations attending at that remarkable Congress (including EOS, the only registered expatriate association) marked the birth of the national federation FEDAO.

The 'Federación de Asociaciones de Ostomizados' (FEDAO) was formally constituted and inaugurated with the eight Spanish ostomy associations and EOS at Zaragoza in September 2006. EOS, as a 'vocal' member of the Junta Directiva, was responsible to it for international liaison. It was registered in Madrid and was initially active in representing us to the Ministries, etc., but sadly, this is no longer so. It exists now in name only to provide a listing of its former member associations in the Regions.

Following that Bilbao meeting, the new national federation was to be administered by the enthusiastic and active Eugenio de Lucas (sadly now deceased), the President of AOMA. AOMA celebrated annually (!) to mark their chosen World Ostomy Day and other associations also played their part. In Jávea, EOS put on useful events mainly to mark the triennial WOD's up until 2012. However, apart from the publicity distributed locally by the associations at such events, the IOA/EOA Charter of Ostomates Rights is not well promoted or recognised.

The new and very capable president of AOMA is an English speaking lady - Pilar Monteil Llorente, a former employee in the Ministry of the Interior and former FEDAO secretary. It is Pilar who currently maintains contact with the regional associations.

To record, albeit in brief, the earlier history of organisation of ostomists here in Spain, I must mention the early work of a British nurse with fluent Spanish; Barbara Foulkes, who came to Spain with the British company Bristol Myers Squibb. Their subsidiary became ConVatec. She was an ostomist and led the way in the training of Spanish nurses in Pamplona, the main nursing school. Many years later in 1996, after my own operation, whilst seeking help I was delighted to hear that she lived in Jávea. However, I was too late. She had passed away in 1992 after the return of her own illness. I am the custodian of her records.

I do not have records of the story of the Association that existed in Madrid under the leadership of Sr. Jesus Fano. With the help of an EOS family member in Madrid, in 2002 we located his locked office, but even with the assistance of the building concierge we were unsuccessful in finding him. Sr Fano was well-known in IOA circles for his attendance at Congresses over several years.

AYUDARTE, an organisation run by Sr. José Durante, did bring me help and information for which I was grateful. Our local association (then EOCB, subsequently EOS) grew and was given a 2 -room 'consulta' space by the Jávea Amigos Europeos ambulance service. At our monthly meetings it became clear that some members, established ostomates, had been 'suffering in silence' with problems but without any stoma check-up for years! Ayudarte provided a lovely nurse (Gloria) to examine those who wished it. The rooms were full on her days: Peace of mind! Sr. Durante was later to support our now-famous inaugural garden party in 2002.

The main professional nursing body is SEDE, and the past president José Mula expressed interest and concern for ostomists when he visited ACO the (now defunct)

association of Barcelona. I have found little interest on the part of the stoma nurses to join SEDE and only one nurse (in Seville) belonged to WCET.

It seems that, in the main, neither the nurses nor surgeons (with the notable exception of Bilbao's Dr Bienvenido) have made any attempt to encourage patient groupings. They are admittedly very busy and stay within the allotted time of the consultations. He/she is expected, as well as taking care of ostomy patients, to visit the hospital wards, to assist in the early morning blood analysis unit and to be a Theatre Nurse. Understandably perhaps they do not make themselves available after hours for a convivial cup of tea with the ostomists as is reported to happen in UK hospitals.

In Spain, the usual situation is that the patient who brings his stoma worries to his GP is sent to a Psychologist who takes over - presumably with only little knowledge of the realities of life with a stoma that they have learnt from previous patients. Surgery, however, in Spain is generally well regarded, but there have been several instances coming to our notice that were unsuccessful.

All professionals in Spain must be registered in a 'Colegio', the appropriate body instituted and given various protections by decree, and with a most important standing in the community. The Colegio sets the rules of conduct as well as fees and ensures exclusive dominance of its field. Its privileged position seems to foster remoteness from those it is intended to serve and in practice is restrictive of its members' outside involvements.

## **The 'Expatriate Ostomates of Spain' (EOS, formerly EOCB)**

EOCB was founded in Jávea on the Costa Blanca in 1997 by Cynthia Robinson. It comprised a fluctuating group of local ostomists who, like her, sought mutual support and the opportunity to assist others. Contacts were made through doctors and the local hospitals, and by referrals from the British Colostomy Association. We reciprocated in kind with the CA, the IA, and the UA who have always been most helpful to us. EOCB became EOS on its registration as a national association in 2003.

In 2002, EOCB found and invited the then known Spanish associations to come and celebrate WOD 4 at a garden party in the sunshine with the IOA slogan 'YES, WE CAN' - and this we all did! We could not guess the future events at that time. We provided everyone with IOA information supplied by the then president, Heinz Wolf, including the 'Ale Tiene' booklets which proved most popular.

EOS was a multinational voluntary charitable association of ostomates and friends, active locally, nationally and internationally. It was a full member of the Spanish

Federation of Ostomy Associations (FEDAO) which had its early beginnings and held its first recorded meeting here in Jávea in September 2002. Through this Federation, we were represented in Madrid in the continuing search for better care for ostomates in the Spanish Health Services. It was through our international contacts that our surplus items were sent to distribution points for onward shipping to parts of the world totally lacking in such supplies.

In 2004, EOS was invited to join the International Ostomy Association (IOA) and took its seat on the World Ostomy Council at the Porto Congress in that year. Our international connections through the IOA were greatly strengthened at the Puerto Rico Congress in August 2007 at which we represented Spain through FEDAO (although the Federation itself had yet to join IOA). At the 2010 Meeting in Frankfurt, the IOA re-organised devolving the leadership to the three Regions – Europe, Asia and the South Pacific, and the Americas – EOS then becoming a Member of the European Ostomy Council (EOA).

EOS was formally wound up and deregistered in 2015 when no successor to Cynthia could be found. Its work in assistance of ostomates is continued through the EOS Information Service.

**EOS Information Service** is an independent non-profit-making national service, based in Jávea using telephone and email communication. It is dedicated to the support of all ostomates in Spain, residents and visitors, but focussing on the expatriates in view of the particular problems they face.

## **Product supplies in Spain**

Imports continue from four principal suppliers - ConVatec, Coloplast, Hollister and Braun. Some Welland products are also now available.

Not all product lines are available here (eg, Coloplast Sensura). We received complaints about the withdrawal from the market (this without notice) of ConVatec short length drainable ileo bags, the long ones being totally unsuitable for short people.

We are told that the ConVatec catalogue is only available in Spain to stoma nurses, hospitals and pharmacies. This would seem to show a complete lack of trust in the integrity of elected representative associations, and of understanding of the ostomy patient's need for information. At the same time we can only repeat that there are few stoma nurses in the country and these are not necessarily accessible without formal prior appointment.

The chain of supply is from the importer agency to regional warehouses which, in turn, supply the pharmacies on the latter's order. The pharmacies enjoy a monopoly on the retailing of ostomy products: they carry only minimal stocks and rely generally on obtaining their customer's prescribed requirements via their daily delivery arrangements with the warehouses. This service is usually very good.

## **Social Security Service**

Spain, fortunately, has a comprehensive contributory social security system and health service with major hospitals in all provinces and busy clinics in most towns. All Spanish and legally-resident expatriates can register and have free access through their allocated doctors. The rules for obtaining medical prescriptions have changed from time to time during this period of economic recession but, at present, they are in the form of a detailed personal schedule obtained from the doctor and fulfilled by the pharmacy on due dates and for a small charge. The Valencian region (and perhaps other regions too) subsidises these charges so that prescribed items are effectively free; otherwise prescription charges are at 10% of cost but subject to an upper limit for each item (currently €4,20) and to an overall personal monthly quota which may be either €8 or €18 according to income status: beyond that quota, prescribed supplies are dispensed free of charge. The pharmacies often provide an excellent complementary advisory service: some have laboratory facilities, and can thus rapidly provide analysis results which are normally accepted by the Health Service doctors.

Ostomy products available on prescription have a national Code Number and are limited to the required pouches or other necessary equipment: skin care is not provided for and must be purchased at full cost over the pharmacy counter. General Practitioners do not normally have the necessary Code details and may rely on their patients to supply these. The associations can assist their members with this information, subject to the patient's own scant knowledge of their own condition and of the options available to them.

Ostomy surgery is carried out at most major hospitals, generally with expertise and care. This same standard pertains in the private system. However, overall there are criticisms in the poor availability of after-care. Very often patients are discharged from hospital prematurely, with little understanding of the essentials of stoma management and of the means of procurement of supplies. The supply companies try to assist patients with videos and written material (usually in Spanish). We are proud that EOS has also assisted callers across Spain by posting many excellent explanatory booklets

to new European patients. They were kindly supplied to our office from Coloplast UK. Booklets in other languages have also been mailed to enquirers.

On occasion, private surgeons need to do the pre- and post operative work of a stoma nurse. Qualified stoma therapist nurses (ETs) are available in some hospitals but in some regions they are very sparsely distributed. SEDE, the representative national professional body for ETs, lists a membership of only about 25.

## **Current developments in ostomy care in Spain**

It was announced in the Europa Press (8<sup>th</sup> Sept 2016) that the Spanish Association of Coloproctology (AECOP), the Spanish Society of Expert Nursing in Stomatherapy (SEDE) and the company Coloplast, are working to create the White Book of Ostomy, in collaboration with the Regional Observatories of Ostomy 'Oros' Project. It is a document aimed at provision of information on the current situation of ostomy in Spain that will allow a better approach to patients and better training of the stoma nurses.

Quoted in **DIARIODICEN** (7 septiembre, 2015 ), Elena García, of the Surgery Service of the Hospital 12 de Octubre in Madrid, said that this book "arises from the need to know the reality that professionals, patients, relatives and caregivers face every day, from that knowledge, global and real, to put in value the work done by professional experts in stomatherapy and pose new challenges." And, per Miguel Ángel Parada, stomatherapist of the Hospital Vinalopó Salud (Valencia), this work "will show the helplessness in which the ostomy patients are often immersed as well as the lack of recognition of the work of the expert nursing in stomatherapy"

The Diariodicen article continues explaining that "The book was born as a consequence of the OROS Project (Regional Observatory of Ostomy) launched in 2014 by the Coloplast Ostomy Forum (COF), a group that brings together almost one hundred nurses specialized in ostomy throughout Spain and representing the more important hospitals. These, together with the Spanish Society of Expert Nursing in Stomatherapy (SEDE) and the Spanish Association of Coloproctology (AECOP) are working on issues related to the care of the ostomy patient and will soon request the endorsement of the General Nursing Council (CGE), chaired By Máximo González Jurado."

That change may be afoot in Spain is evidenced by the following statement (also reported in Diariodicen) from the President of the Spanish Association of Coloproctology, José María E. Navascués. He affirms that the White Book will be

key to "adapt resources and programme the future professional and care." and considers fundamental the figure of the specialized consultant: "coloproctology is to surgery," he points out "what stomatherapy is to nursing". The one without the other is incomplete or absurd. Therefore, there can be no coloproctology unit (or advanced colorectal surgery) without an intimately linked stomatherapy." And he points out that "no medical, nursing, or surgical service head of a tertiary hospital should allow the practice of advanced colorectal surgery without a recognized ostomy unit.

## People and organisations mentioned

La Asociación Española de Coloproctología (AECP),

La Sociedad Española de Enfermería Experta en Estomaterapia (SEDE)

Consejo General de Enfermería (CGE), presidido por Máximo González Jurado.

Observatorios Regionales de Ostomía (Proyecto Oros) coordinado por Sagrario Leonor y José Luis Cobos, asesor del CGE, puesto en marcha en 2014 por el Coloplast Ostomy Forum (COF), colectivo que reúne a casi un centenar de enfermeras especializadas en ostomía de toda España y que representan a los centros hospitalarios más importantes.

Elena García, del Servicio de Cirugía del Hospital 12 de Octubre de Madrid

Miguel Ángel Parada, estomaterapeuta del Hospital Vinalopó Salud (Valencia)

Maribel Iborra, coordinadora asistencial de Planta del Hospital Clinic i Provincial de Barcelona

Mayte San Emeterio, de la consulta de Cirugía del Hospital de Cruces, en Bilbao

Manuel Bona, presidente de la Sociedad Española de Enfermería Experta en Estomaterapia (SEDE)

José María E. Navascués, especialista en Cirugía General y Digestiva de la Policlínica Guipúzcoa, presidente de la Asociación Española de Coloproctología

Asociación de Ostomizados de Madrid (AOMA)

Asociación de Ostomizados de Bizkaia (Bilbao) (ARGIA)

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